

**YOUNG PEOPLE'S JOURNEYS WITH CANCER AND FACTORS THAT
INFLUENCE THEIR EXPERIENCES**

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**A thesis submitted in partial fulfilment of the requirements of the University
of East London for the Professional Doctoral Degree in Clinical Psychology**

May 2013

ABSTRACT

There is a wealth of literature exploring the experiences of children (aged 13 and below) with cancer but little focusing on young people aged between this and adulthood (i.e. 18 and above). A diagnosis of cancer during this time may add to the stressors associated with a 'normal' transition to adulthood. It may also impact on their relationships, quality of life and psychological wellbeing, amongst other components of their lives. In addition, there is limited research exploring factors that young people find helpful during their journey with cancer.

This study therefore aimed to investigate young people's experiences of their journeys with cancer and factors that had influenced these. Semi-structured interviews were conducted with ten participants who had taken part in a narrative therapy intervention at a London hospital. Participants comprised 5 males and 5 females with cancer, aged 13 to 21. The sample was also heterogeneous in terms of diagnosis and time since diagnosis. Interviews were analysed using a critical realist thematic analysis.

Three themes were identified: 'it's been up and down', 'I'll get through this' and 'impact on the wider system'. They highlight the variety of experiences young people had had and the importance of the contexts in which these took place. They also illustrate the importance of personal support networks, professional support and personal coping strategies that young people found helpful. Finally they highlight the impact of cancer on others.

The findings suggest that it is important for clinicians to remain curious when working with young people with cancer and to listen out for times when they are able to be positive and talk about their positive experiences. They also highlight the importance of the ways in which staff communicate and suggest that an emphasis needs to be placed on differentiating between services for children and young people.

ACKNOWLEDGEMENTS

I would like to thank the young people who volunteered to give up their time to tell me about their experiences. Without them this project would not have come to fruition. I feel honoured and privileged to have met them.

I'd also like to thank my supervisor Dr Ken Gannon and my field supervisor Sara Portnoy for their constant support throughout. Their ideas, comments and encouragement kept me going and I could not have done it without them. Thank you also to all the staff at UCLH for their help in the recruitment process.

Thank you to my friends and family for their invaluable support and listening to my endless rants. Thank you for your patience, for grounding me and for your continuous words of encouragement. Thank you also for dragging me out of the house and maintaining my work-life balance for me.

My family, as always, have been my rock, offering support and believing in me throughout. I will never forget the Friday night dinner where we went round the table trying to come up with a title for the project. Dad, your words of inspiration kept me going and you always know what to say. Mum, the world's greatest proof reader, thank you for reading chapter after chapter and correcting my endless grammatical errors, not only with this thesis but throughout training. Your love and support got me over the finish line. I couldn't have done it without you guys.

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1. INTRODUCTION

This chapter aims to review the literature on young people diagnosed with and treated for cancer. I begin by defining a number of key terms. I then highlight the prevalence and changing trajectory of cancer and discuss the potential impact a diagnosis of cancer and its associated treatment can have on young people. By reviewing this literature, I argue that it may also be important to consider what young people find helpful during their experiences with cancer.

I discuss the potential role for psychology in supporting this population and review the literature for psychosocial interventions. I then focus on Narrative Therapy as a way in which to explore the experiences of young people diagnosed with and treated for cancer. Finally, I summarise the questions I consider to be unanswered and state the research questions for this study.

1.1. Literature Search

In order to collate the current research, systematic literature searches were conducted. The term 'cancer' was paired with different words and phrases (e.g. mental health, quality of life etc.) and these search terms were entered into the following databases: PsychInfo, PsychArticles, Medline, CINAHL and Google scholar.

These literature searches identified 2815 articles. Filters were then used to make the reading more specific to the research project. Articles included were those that focused on an adolescent population, although some papers referring to child and adult populations were used. Furthermore, meta-analyses and systematic reviews were prioritised due to the large body of literature. Papers adopting qualitative methods were also prioritised given the nature of this research. Papers were excluded if they focused on medical treatment or were not written in English. See Appendix 1 for more details of the search strategies.

1.2. Definitions

1.2.1. Cancer

Cancer is a potentially life threatening disease “caused by an uncontrolled division of abnormal cells” (Stevenson, 2010, p. 253); a process that occurs independent of the need for new cells (Hill & Tannock, 1992). When these cells multiply they can form a malignant growth or tumour (Stevenson, 2010), as well as invade other parts of the body where new tumours may be generated (Hill & Tannock, 1992). For the purpose of this study cancer will be defined as

a sequence of events linked with one another, which begins with the first signs of the disease, continues with treatments, hospitalisations, convalescence, and remission, and ends, possibly, with recurrence or death. (Guex, 1994, p. 58)

This definition was chosen as it allows for a more holistic understanding of cancer and the impact it can have on young people.

1.2.2. Adolescence and Young People

Adolescence is difficult to define as it can be seen as a social construction. It has not always been recognised historically and only began to be acknowledged in the 1950s. Furthermore, it is not seen to exist in some cultures and there are no ‘given’ biological markers that suggest someone is an adolescent.

Nevertheless, Stevenson (2012) defines it as “the period following the onset of puberty during which a young person develops from a child in to an adult” (p. 22). Lewis (1996) furthers this suggesting that it should be seen as a flexible term, referring to individuals between the ages of 14 and 22 and that it may also include those several years either side of this.

This study will, therefore, refer to young people in order to acknowledge the difficulty in defining adolescence and in an attempt to be inclusive of those just outside of the age bracket above.

1.2.3. Young People Diagnosed with and Treated for Cancer

As there is no clear definition of adolescence, there appears to be a lack of research looking at cancer diagnosed during this time and an emphasis is placed on research focusing on childhood cancer (Seitz, Besier & Goldbeck, 2009). It has also been suggested that adolescent oncology may be seen as being situated in between adult and paediatric oncology services, resulting in adolescents being treated within paediatric and adult settings, rather than adolescent specific settings (McTiernan, 2003).

The introduction will therefore focus on the literature referring to an adolescent population but will also draw on the literature focusing on cancer during childhood and adulthood. Given the complexity in defining adolescence, I will refer to young people diagnosed with and treated for cancer (YP) when considering research in childhood and/or adolescence. I will also highlight if research recruited an adult population.

1.3. Why Consider YP

Adolescence has “been described as one of the most difficult stages of life” (McTiernan, 2003, p. 233), where a young person makes the transition from childhood to adulthood. This transition has been associated with many developmental tasks, including: changing schools, developing a sense of self-esteem, forming an identity, establishing social competence, learning to balance family and peer influences, developing and exploring sexuality and adapting to emerging intellectual abilities (Decker, 2007; Havighurst, 1972; Lewis, 1996). It has been argued that these ‘normative’ developmental transitions can be stressful and overwhelming (Decker, 2007).

A diagnosis of cancer during this transition is likely to affect every aspect of a young person’s life (Epstein, 2004). It may increase the stress of the ‘normative’ developmental tasks described above and put demands on individual’s coping skills (Seitz, Besier & Goldbeck, 2009). For example, a diagnosis of cancer may

challenge young peoples' sense of self-esteem and self-image during a time that they are being developed (Lewis, 1996).

YP may also have their education disrupted, which may result in them losing touch with their peers or struggling to keep up with academic work. It may also lead to feelings of isolation or feeling 'different' (Barlow & Ellard, 2006). In addition it may impact on their independence; the diagnosis of and treatment for cancer is likely to result in young people becoming more dependent on their parents/carers, medical staff and the hospital, which may set young people apart from their peers (Seitz, Besier & Goldbeck, 2009).

It could therefore be argued that YP have to deal with dual stressors: transition to adulthood and cancer (Seitz, Besier & Goldbeck, 2009). These dual stressors may be overwhelming for many young people as they are unlikely to have experienced dealing with difficulties of this magnitude (Decker, 2007). The young person's capacity to negotiate the impact and effects of cancer, whilst transitioning, can be seen as key to successfully managing these developmental disruptions (Olsson et al., 2003).

1.4. Cancer Prevalence and its Changing Trajectory

Cancer is currently the leading cause of death worldwide (World Health Organisation, 2011) and the fourth largest cause of death in children and adolescents aged between 1 and 19 (Ries, Percy & Bunin, 1999). Although it is more prevalent amongst the elderly (Office for National Statistics 2009 & 2011), young people are also affected. Approximately 1200 children aged 0 to 13 and 2100 young people aged 13 to 24 are diagnosed with cancer in the UK each year (Office for National Statistics 2009 & 2011; Teenage Cancer Trust 2010).

Although these statistics seem quite shocking, a diagnosis of cancer during adolescence is actually quite rare; "0.5% of all cancers occur in young people" (Teenage Cancer Trust, 2010). In 2009 approximately 920 young people in the UK were registered and treated for cancer (North West Cancer Intelligence

Services, 2009) and it is estimated that each year in the UK approximately 1 in every 6000 adolescents aged between 15 and 19 is diagnosed with cancer (Office for National Statistics, 2000).

It is worth noting that different cancers appear to be more prevalent at different ages. For example the most common cancers amongst 13 to 18 year olds are brain tumours, lymphomas and leukaemia. The most common cancers amongst 19 to 24 year olds are soft tissue cancers, germ cell tumours and lymphomas (Teenage Cancer Trust 2010). This is important to take into consideration given the prognosis of these different diagnoses. Survival rates for those diagnosed with leukaemia has increased by 20% over the last two decades whilst it has not changed as much for those diagnosed with soft tissue cancers, brain tumours and bone cancers (Teenage Cancer Trust 2010).

Nevertheless, with advances in technology, survival rates for all cancers have improved over the last four decades (Epstein, 2004; Robison et al., 2009), with three-quarters of YP now surviving (Teenage Cancer Trust 2010). YP are no longer considered as having a fatal illness, with cure being the likely outcome for most (Bruce, 2006; Robison et al., 2009). Consequently, it is recommended that YP receive long-term follow-up to help screen for and manage the possible psychological impact and late effects¹ of cancer (Children's Oncology Group, 2008), amongst the many other possible impacts it may have. It may, therefore, be important for services to consider both the current and/or immediate impact cancer may have on YP, as well as the potential longer-term impacts.

Taking the above into consideration, it could be argued that YP are an increasingly important population to study (McDougall & Tsonis, 2009). This may allow us to understand the impact that the diagnosis of and treatment for cancer can have on YP during a time of transition. It should also enable us to consider the impact cancer has on those around them, as well as allowing us to consider what services should perhaps be offered to support this population.

¹ These refer to the possible long term impacts some of the treatments may have.

1.5. The Impact of Cancer

Stam, Grootenhuys and Last (2001) suggest that there is a growing wealth of literature focusing on YP and the physical and cognitive impact cancer can have, but that far less consideration is given to YP's social and emotional functioning. One reason behind this may be that an emphasis is placed on curing cancer within the health care system and as a result less attention is paid to the impact on the individual (Epstein, 2004).

However, there is an increasing number of studies focusing on the psychosocial impact that a diagnosis and treatment can have (Bruce, 2006; Stam, Grootenhuys & Last, 2001). This section reviews the literature that highlights the psychosocial impact of cancer on YP.

1.5.1. Physical Impact

Many of the treatments associated with cancer have several side effects which may have an impact on the psychosocial well-being of YP. For example, some treatments may affect their appearance (e.g. hair loss; change in weight), cause fatigue and/or affect mobility (Larcombe et al, 1990; Lopez, 2011; Woodgate, 2000). McCaffrey (2006) highlights how these side effects may have an impact on young people. For example YP may feel the need to disguise hair loss (e.g. by wearing a hat) or be unable to take part in certain activities. Side effects may also draw unwanted attention from others and YP may be subject to personal questions that they may or may not want to answer (McCaffrey, 2006).

Woodgate (2000) also highlights the physical impact cancer can have in her critical review of the qualitative research relating to YP. She reviewed 21 papers and one theme she identified was 'cancer hurts in many ways'. She found that the majority of research with YP focuses on pain, whereby the pain associated with treatment was seen as the worst part of the cancer experience. This critical review also highlighted how cancer can cause fatigue, both physically and mentally.

Some cancer treatments may also have a long-term physical impact on young people. For example, chemotherapy may affect how hair grows back and it may also have an impact on fertility (Roberts, Turney & Knowles, 1998). In addition, some diagnosed with osteosarcoma may require an operation or an amputation. As mentioned above, this may result in YP being asked personal questions that they may wish to avoid (McCaffrey, 2006).

It could also be argued that these physical impacts take place at a time when YP are developing a sense of identity and self-esteem, amongst the many other 'challenges' of transitioning from childhood to adulthood described earlier. It may be that these physical impacts affect the 'normal' transitions, which returns us to the idea of YP experiencing dual-stressors (Seitz, Beiser & Goldbeck, 2009).

1.5.2. Psychological Impact

This section includes statistics and references to mental health diagnoses to highlight the potential psychological impact of cancer on young people. These statistics should be seen as accompanying the other discourses around cancer, rather than holding the assumption that these diagnoses and statistics are reliable and valid².

When conducting the literature search, it became evident that there are inconsistent findings regarding the psychological impact cancer may have on young people (McDoughall and Tsonis, 2009). Whilst the majority of the research highlights that YP may experience mental health difficulties, there appears to be a lack of reliable information as to whether this is more prevalent than in the general population.

Ruland, Hamilton and Schjødt-Osmo (2009) conducted a systematic literature review on the potential behavioural, psychosocial and physical problems children with cancer may experience whilst unwell. They also looked at how YP spoke

² From an epistemological point of view the reference to diagnoses and the use of statistics in making claims about the impact of cancer on young people, in addition to the exploring the discourses about what YP find helpful, could be seen as conflictual. This will be discussed in more detail in the methodology.

about these and how these experiences varied during their journey with cancer. They found that of the 219 problems identified in the 110 articles they reviewed, 36% of these were psychological and/or emotional (e.g. dysphoria). They also reported that these difficulties were the most frequently studied and that few studies examined how these varied over time.

Similarly, Eiser, Hill and Vance (2000) systemically reviewed twenty studies that looked at YP and the psychological impact cancer may have. Only one study that they reviewed reported more psychological 'difficulties' amongst YP, when compared with the general population, with the rest reporting no difference. They also reviewed one study that reported YP experiencing fewer psychological 'difficulties' when compared with a control group. The review concluded that YP did not experience 'problems' with their mental health or self-esteem more than matched controls. However, the authors acknowledged the difficulty in comparing different methodologies.

Stam, Grootenhuys and Last (2001) also reported similar findings when they systemically reviewed fifty two studies that investigated the effectiveness of 'emotional-adjustment' in YP. Although some mental health difficulties were identified, the number of participants reporting 'significant' mental health 'difficulties' was consistent with published norms. For example, they report that the prevalence of symptoms of 'anxiety' and 'depression' amongst YP is similar to that in the general population.

Other research has focused on Post-Traumatic Stress Symptoms (PTSS)³. When assessing the proportion of YP that report PTSS, Stuber et al. (1994, 1996) found that 30% of YP had experienced mild PTSS, 17% had experienced moderate symptoms and 12.5% had experienced severe symptoms. These results were also correlated to the YP's appraisal of the intensity of treatment. However, when compared to healthy controls, this population does not appear to report more PTSS (Bruce, 2006). In fact some research suggests that YP may

³ There are numerous controversies relating to the relationship between the diagnosis of Post-Traumatic Stress Disorder (PTSD) and cancer. Therefore the research around this area tends to focus on PTSS rather than PTSD (Bruce, 2006).

experience Post Traumatic Growth (Barakat, Alderfer & Kazak, 2006) which can be “defined as the cognitive process by which those who have experienced trauma apply positive interpretations to and find meaning in the traumatic event” (Barakat, Alderfer & Kazak, 2006, p. 414). However, there is limited research exploring this with YP.

The research described above suggests that although YP may experience mental health and psychological difficulties, this may not be more than the general population and some may experience ‘growth’. One could therefore argue that it is important to explore what makes it possible for this population to keep going and whether cancer has any positive impacts (Eiser, Hill & Vance, 2000; Stam, Grootenhuis & Last, 2001). This literature also highlights that it may be important to consider what factors are associated with distress. This may allow professionals to identify YP who may want support and what support would be most appropriate.

1.5.3. Quality of Life

Although both Quality of Life (QoL) and Health-Related Quality of Life (HRQL) are difficult to define, they are referred to here as they allow for comparisons to be made to ‘normal’ populations. It is important to acknowledge the limitations of these measures, such as the cultural assumptions (Oliver & Holloway, 1995), when considering this literature.

Similar to above, the literature on QoL and HRQL with YP suggests that there are inconsistent and contradictory findings (McDoughall & Tsonis, 2009). Whilst some research suggests that YP’s QoL and HRQL may be impacted, other research contradicts this postulating that they report similar QoL and HRQL when compared to those of a similar age within the general population. This may be, in part, due to the challenges regarding the validity of these tools and that it may not be possible to quantify QoL and HRQL. These concepts have been subject to criticism as they can be seen to locate the phenomenon within the individual, thus viewing it in an absolutist way (i.e. a QoL score represents a state that does not depend on the overall context) rather than viewing it as a social product (Rapley,

2003). It is therefore not surprising that there are inconsistencies given the problematic nature of these concepts. These contradictory and inconsistent findings may also highlight the importance of individual difference and that some YP's QoL and HRQL may be impacted by their cancer experiences, whilst others' may not.

Hudson et al. (2003) found that YP are 80% more likely to report 'clinically significant' QoL impairments than their sibling and are five times more likely to report functional impairment in HRQL. It has also been reported that YP consistently score lower than controls on HRQL scales, such as the physical summary and psychosocial summary (Speechley et al., 2006). Grant et al. (2006) similarly found that YP report lower HRQL scores when compared to the general population.

However, there is also research suggesting that YP are "in good physical health and function well psychologically and socially" (McDoughall & Tsonis, 2009, p. 1232). For example, Maunsell et al. (2006) reports that YP report little, if any, difference in QoL when compared to 'healthy' controls. Furthermore, they found that these differences are often not 'clinically significant'. Similarly, Zebrack and Chesler (2002) reported that YP rated themselves high on several QoL scales, including: their ability to cope, feeling useful, happiness and life satisfaction.

In a recent literature review on the QoL of YP, McDoughall and Tsonis (2009) argue that young people often 'cope' well. They systematically reviewed thirteen studies dated between 2001 and 2008 and found that there is mixed data with regard to the impact cancer can have on young people. They found that most of the studies they reviewed had small, if any, significant differences between those who had cancer and those who did not, with some reporting 'better' psychological well-being. They therefore recommend at the end of their paper that:

qualitative research should be conducted to advance theory and model development, to identify the variables that are most important to QoL from

the perspective of survivors [YP], and to help understand why survivors [YP] maybe enjoy better QoL. (p. 1243)

It may, therefore, be important to move away from these concepts and focus on the impact on YP's everyday lives, such as relationships and school-life.

1.5.4. Relationships

In Woodgate's critical review (2000), described earlier, she highlights the impact cancer can have on YP's relationships. She reports that YP can become isolated from their friends and family as a result of regular hospitalisation and hospital visits. Similarly, Enskar et al. (1997) reported the impact cancer may have on YP's relationships; they found that YP described their family as becoming overprotective since they had been diagnosed with cancer and that their desire for privacy was overridden by their families' concerns. Seitz, Beiser and Goldbeck (2009) also reported similar findings, as mentioned earlier, highlighting that YP's relationships are different to those of their peers as cancer may impact on their independence and they may become more dependent on their parents/carers (Seitz, Besier & Goldbeck, 2009).

In contrast, the literature also highlights the importance of relationships and social support. Some YP describe their personal support networks as helpful in facing some of the challenges associated with cancer (Eiser, 1994; Haase & Rostad, 1994; Woodgate, 2000), with parents seen as being the most significant source of support (Hockenberry-Eaton & Minick, 1994; Woodgate, 2000). For example, Hockenberry-Eaton and Minick (1994) conducted a study with 21 children, aged 7 to 13, who were being treated for a variety of cancers and found that family members, especially parents, can provide YP with the courage to fight and overcome their fears. Similarly, Anderzén-Carlssona, Sörlie and Kihlgrena (2012), when interviewing 6 adolescent women, found that having the emotional support of significant others was helpful as it enabled them to cope 'better' with the impact cancer was having on them.

It can therefore be argued that YP's relationships may be affected by cancer but that they may also be important to help support YP. This seems essential for professionals to consider when offering support to YP as relationships may act as a resource.

1.5.5. Returning to 'Normality'

Although 'normality' may be difficult to define, as it can be deemed a social construction, the literature appears to highlight its importance and YP's desire to return to it. For example, one theme highlighted in Woodgate's critical review (2000) was 'I am normal but may do things differently'. She argues that although YP may have lives that are different from the general population, it "does not mean that they or their responses are abnormal" (Woodgate, 2000, p. 219) and therefore research should not focus on comparisons with control groups. Furthermore, she suggests that YP do not approach their experiences from a 'deficit-based' perspective, but rather see themselves as 'normal'.

This is supported by other research, such as Rechner (1990) who interviewed five YP aged 13 to 17. She found that participants viewed themselves as 'normal' and that they found ways to continue to feel this way, rather than allowing themselves to feel 'different'. For example, she reports that participants developed a philosophy of positivity in an attempt to try and get on with life. Weekes and Kagan (1994) reported similar findings when interviewing 13 adolescents being treated for cancer; they found that YP wanted to regain a 'normal' life and be able to do the activities that they had not been able to do. Haase and Rostad's study (1994), in which they interviewed seven YP, aged 5 to 18, also furthers this idea – they suggest that YP may begin to redefine 'normal' following their experiences with cancer. Lopez (2011) also reported similar findings in her research exploring the transition experiences of YP. Participants in this study saw cancer as a transition in their lives and something that they both wanted to and would overcome. However, this study also highlighted that, despite participants' desire for 'normality', this was influenced by the fear of relapse.

Other challenges to returning to 'normality' have also been highlighted in the literature. Palmer et al. (2007) ran a focus group with six YP to explore their physical and social needs. They highlighted several themes that can be considered as challenges to returning to 'normality' including: fear of relapse, not being as healthy as before diagnosis and becoming and remaining independent. They also highlighted that participants experienced uncertainty about the future and concerns about obtaining and/or maintaining employment. This again highlights the 'dual stressors' that YP may have to face and how cancer diagnosed at this time challenges some of the transitions that YP may face (Seitz, Beiser & Goldbeck, 2009).

1.5.6. School

As mentioned earlier, cancer can also be seen to impact YP's school experiences and can cause disruptions (Roberts, Turney & Knowles, 1998). Haase and Roastad (1994) found that participants spoke about missing school and how this was affecting them. They describe how missing school led YP to feel isolated. They also report that participants wanted to return to their 'normal' routine and be at school. Similarly, Palmer et al. (2007) found that participants reported how cancer may impact their ability to finish school and/or exams.

However, it seems that cancer does not only have a negative impact on schooling but that it is something that YP keep in mind as it allows them to look towards the future. For example, Woodgate (2000) highlights in her critical review that some YP find it helpful to think about going back to school and some YP find it helpful to go back to school. It could therefore be argued that this may be a way for YP to return to 'normality' and what they were doing before cancer came into their lives.

1.5.7. Positive Impact

Although a large proportion of the research considering YP is 'problem-saturated' (Parry & Chesler, 2005), there is some research that looks at the strengths and resilience of YP and the positive impact cancer may have had. For example, as

described earlier, some research focuses on concepts such as post-traumatic growth.

Parry and Chesler (2005) interviewed 50 survivors of childhood cancer aged between 17 and 22 and found that, although participants reported that there were certain aspects of their cancer experiences that they found difficult, they also reported a number of positive changes. Sixty five per cent of participants reported increased psychological maturity and 61% reported greater compassion and empathy. Participants also reported having new values, priorities and strengths as a result of their experiences with cancer. Similarly, Engvall et al. (2011) found that, although YP had had negative experiences, the majority of their participants had also had positive experiences. Participants in their study reported how cancer had brought about positive changes regarding YP's self-perceptions and philosophy on life. Other research highlights that YP believe that having cancer has meant they have become more mature and feel that it has given them the desire to physically and mentally further themselves (Bearison, 1991; Enskar et al., 1997; Haase & Rostad, 1994; Hockenberry-Eaton & Minick, 1994; Woodgate, 2000).

It seems that, if asked about the possible positive impact cancer may have had, YP are able to name these alongside the other possible impacts. It can therefore be argued that reflecting on their experiences with cancer from a positive perspective may be helpful as it may help YP reflect on whether there have been any positive, as well as negative, aspects. It may then be important to move away from the deficit-based model and consider whether YP think there are any positive aspects to having cancer and whether there are factors not currently considered that professionals should be addressing.

1.6. What YP Find Helpful

In addition to the literature highlighting the positive impact cancer can have on YPs' lives, it has been argued that it is also important to explore what helps YP to keep going (Eiser, Hill & Vance, 2000; Stam, Grootenhuys & Last, 2001). This

may relate to the apparent recent shift from deficit-based to competence-based psychological models, with more of an emphasis beginning to be placed on the latter (Kazak et al., 2007). However, this is often overlooked and there seems to be limited research in this area (Stam, Grootenhuis & Last, 2001; Bruce, 2006)⁴.

Zaza, Selick and Hillier (2005) interviewed 292 adult cancer outpatients in America about seven different coping strategies, including: breathing exercises, hypnosis/self-hypnosis, meditation, music, muscle relaxation, prayer and visualisation/imagery. They also asked participants about services they were able to access, including: family counselling, individual counselling, religious support and support groups. They found that prayer was most commonly used (it was reported by 64% of participants) and that the other strategies were used by less than a third of their participants. However, it is important to highlight that this study comprised an adult sample.

With regard to YP, Woodgate (2000) identified several factors that they found helpful. Similar to above, religion, god and prayer were seen to be helpful to YP. She also reports that YP found getting on with life, getting used to things and keeping busy helpful. Other research has highlighted that a belief in powerful others, such as doctors (Maurice-Stam et al. 2009), and talking about the possibility of death or the death of others who have been affected by cancer (Bearison, 1991) can be helpful to some YP. In addition, optimism about the future, having positive experiences, wishful thinking and hopeful images have been seen as helpful (Maurice-Stam et al. 2009; Wu et al., 2009). YP have also reported that it is helpful to seek information (Engvall et al., 2011) and search for meaning as this may reduce uncertainty (Manne et al., 1993; Maurice-Stam et al., 2009; Tyc et al. 1995; Woodgate, 2000).

⁴ It is important to reiterate that some factors that YP find helpful have been integrated throughout the introduction (e.g. relationships and school).

1.7. The Role of Psychology and Psychosocial Interventions

Given the inconsistencies in the literature about the impact cancer may have on YP and the lack of research on what YP find helpful (Stam, Grootenhuis & Last, 2001), it is important to emphasise that YP may have different experiences. It therefore seems imperative to consider these rather than trying to fit individuals to models or theories (Sorgen & Manne, 2002).

Psychology may play an important role in offering psychosocial interventions that can be tailored to individuals and their circumstances (Scott et al., 2003). This is supported by the National Institute for Clinical Excellence (NICE) guidelines (2004) which posit that psychological support should be available to all cancer patients. This is not to say that everyone will need and/or want support, nor should 'normal' distress be pathologised, but that psychology may take a role in positioning YP and their families as 'experts' so that psychosocial interventions that are fitting for this population can be developed and furthered, ensuring that what they find helpful is offered (NICE, 2005). Depending on what YP find helpful, psychology may take the role of offering support to those who are 'distressed' or experiencing 'difficulties' and/or those who wish to contextualise their experiences and/or reflect on what is helping them to keep going.

Newell, Sanso-Fischer and Savolaninen (2002) conducted a systematic review of psychological therapies for cancer patients and they report that psychological interventions may be helpful to address some of the impacts discussed earlier. Their findings suggest that psychological interventions may help reduce the impact of pain and improve patients' immune functioning, as well as helping with other physical impacts associated with cancer, such as nausea and fatigue. They also report that psychological interventions can be helpful to those who are experiencing 'distress', 'depression' and 'anxiety'. In addition they found that psychological support may be helpful in addressing patients' QoL, overall functioning ability and interpersonal relationships. However, it is important to note that only 13% of the studies in this review were with YP.

Psychological interventions may also be offered to support those who may not be experiencing 'distress' but wish to reflect on the impact diagnosis and treatment has had and how they have been able to keep going, something that YP have described as helpful (Hokkanen et al., 2004). For example, as described earlier, some YP may describe positive experiences and/or wish to focus on returning to 'normality'. Psychological interventions may be more solution-focused in thinking about how these can be acknowledged, at the very least, alongside the other potential impacts cancer may have. This is also supported by Newell, Sanso-Fischer and Savolaninen's review (2002) in which they report that psychological support focusing on this may be helpful.

As both deficit-based and competence-based psychological models may be helpful one could argue that these interventions should be available to YP. However, there do not appear to be standardised psychosocial interventions (Kazak et al., 2007). Furthermore, there appears to be a lack of evidence-based interventions for YP focusing on the individual's coping and adaptation (Sawyer et al 2007) and those that do exist appear to be in the early stages of development (Kazak, 2005). As a result interventions often vary between services (Kazak et al., 2007).

1.7.1. Psychosocial Interventions for YP and their Evidence Base

As described earlier, the literature appears to place an emphasis on childhood cancer (Seitz, Besier & Goldbeck, 2009) and YP are often seen in paediatric or adult settings (McTiernan, 2003). However, YP can be seen as different as they are subjected to dual-stressors: the diagnosis and treatment of cancer and the transition into adulthood (Seitz, Besier & Goldbeck, 2009). As a result their experiences may be different to those in a paediatric and adult setting and the evidence-base for psychosocial interventions for these populations may not be relevant. For example, interventions for adults may place an emphasis on managing the pain and/or psychological distress associated with cancer whilst YP may wish to reflect on this as well as the impact that diagnosis and treatment

has had on their self-image, as this may be developing concurrently (Lewis, 1996)⁵.

Taking the above into consideration, there appears to be a limited evidence-base for psychosocial interventions for YP (Seitz, Besier & Goldbeck, 2009). This is not to say that there are not psychosocial interventions available but rather that there are few that have been empirically investigated. Given the current demand within the NHS for evidence-based practice, this is becoming more of an expectation in order for interventions to continue.

Petersen et al. (2005) state that cognitive-behavioural interventions are most commonly used; they have been seen as helpful in increasing a sense of control and minimising some of the side effects associated with the treatments. They argue that one reason that these approaches may be dominant is that they fit with the medical philosophy of identification and treatment. However, it is important to highlight that, although Cognitive Behaviour Therapy (CBT) is often the dominant approach for Clinical Psychologists, it is not without its critics (Moloney & Kelly, 2004; Summerfield & Veale, 2008). For example, Pilgrim (2010) posits that CBT can be seen as a 'technological' fix for a specific problem (e.g. pain or low mood), rather than considering the wider context (e.g. cancer). CBT can be seen to locate difficulties within the individual and focus on symptoms (e.g. low mood) rather than engaging with the person as a socially-situated individual. It is a problem-saturated approach and thus impossible to adopt unless there is a problem/diagnosis. This may be problematic for a number of reasons. Firstly, as argued by Boyle (2011), CBT places an emphasis on difficulties that are currently present and how these are maintained. As a result, questions about the impact of adverse experiences (i.e. cancer) may be asked about less often and are rarely answered. Secondly, by focusing on difficulties, professionals run the risk of suggesting that individuals need to change rather than the problem itself (i.e. cancer) needing to change (Moncrieff,

⁵ This example has been offered as one idea of how these populations may differ, in an attempt to emphasise the need for interventions tailored specifically towards YP, rather than suggesting that this would be the same for everyone.

Dillon & Rapley, 2011). Therefore, one could argue that when the focus is placed on difficulties and this is prioritised, the person and their contexts are side-lined.

This fits with the literature with YP, which seems to focus on specific problems, such as mental health diagnoses and QoL, despite there being inconsistent findings. Although there is some literature exploring YP's wider contexts, such as their relationships and school, this is still in its infancy (Woodgate, 2000).

Although CBT has been seen to be helpful (Petersen et al., 2005), it may also be helpful to conduct research with YP who have taken part in other interventions that consider the broader contexts, as this may help professionals to have a greater understanding of what it is like to be a young person diagnosed with and treated for cancer and the impact it can have on YP and their contexts. This, in turn, may allow professionals to think about what interventions may be helpful and when..

As mentioned above, Newell, Sanson-Fisher and Savolainen (2002) conducted a systematic review of 627 articles which looked at 329 psychological interventions for cancer patients, although only 13% of studies reviewed comprised samples with YP. In this review they outlined different therapies that have been seen as helpful and make tentative recommendations about the uses of these therapies, although no one intervention can be recommended. They purposefully use the phrase 'tentative recommendations' as they acknowledge that a lot of the studies that they reviewed had poor methodology and/or small sample sizes. They also acknowledge that there is a lot of variation with regard to the types of interventions and outcome measures used in different publications, which can make it difficult to review the literature. Although not highlighted in this review, Jacobsen (2009) acknowledges another difficulty in reviewing the literature: the role of individual difference, in terms of clinical characteristics and levels of distress, can also make it difficult to compare psychosocial interventions.

Despite the challenges in reviewing the literature Newell, Sanson-Fisher and Savolainen (2002) tentatively recommend 'unstructured' counselling and guided imagery for minimising patients' distress and for improving QoL. They also

tentatively recommend group therapy for improving patients' coping skills. Furthermore, they posit that CBT, communication skills training and interventions involving significant others would benefit from further research to consider their efficacy.

More recently, Sansom-Daly et al. (2012) systematically reviewed seven studies that focused on psychological interventions for adolescents with chronic illnesses. They found that most interventions focused on peer-support and psycho-education. They also found that only 32% of the studies reviewed were embedded within a theoretical framework and only 29% focused on coping strategies.

1.8. Narrative Therapy

Although there are few, if any, empirically evidence-based interventions that are consistently used for YP, one therapeutic model that has been seen to be helpful is Narrative Therapy (Epston et al., 2008).

This fits with the recent shift in professionals' understanding of young people's adaptation to cancer, which appears to have moved from a deficit-based understanding towards a competence-based understanding. Deficit-based models have been critiqued for failing "to do justice to the range and meaning of the experiences" (Moncrieff, Dillon & Rapley, 2011) YP may have. Moncrieff, Dillon and Rapley (2011) go on to state that a deficit-based understanding can "render people's experiences as meaningless" and that these models can suggest that something needs to change (i.e. the individual) rather than the problem itself (i.e. cancer). As a result competence-based models have evolved to try and take in to consideration individuals' contexts, strengths and abilities in addressing any given problem (e.g. cancer). These may give more of an understanding to individuals' experiences and factors that have influenced these. Therefore, asking YP who have taken part in a competence-based intervention, such as Narrative Therapy (NT) may provide an opportunity to hear about their

different experiences, rather than focusing solely on the difficulties they have experienced.

1.8.1. NT and YP

It is worth highlighting at this point that NT is one intervention that may serve to offer an opportunity for YP to talk about their experiences, both positive and negative. That is not to suggest that there are not others but that this study focuses on NT.

Although individuals' lives are multi-storied and many stories take place at the same time (Morgan, 2000), all too often therapists hear 'thin descriptions' of their clients' lives (Morgan, 2000). For example, as described earlier, there are differing narratives about YP's experiences. However there appears to be a dominant discourse about the negative psychosocial impact cancer can have on YP, with less emphasis being placed on the discourses of positive experiences and what YP find helpful. As a result certain stories and narratives may be marginalised and subjugated by dominant 'stories' (Freedman & Combs, 1996).

NT also allows participants to discuss and work through their experiences, something that YP have described as helpful in giving them hope (Hokkanen et al., 2004). It may also allow participants to make meaning of their experiences, a coping strategy that has been considered helpful (Parry & Chesler, 2005).

Taking into consideration that YP's experiences may be positive, negative or even both (Smith et al, 1991; Engvall et al., 2011), those who take part in an NT intervention may find it easier to discuss both the difficult parts of living with cancer and what they find helpful, whilst being able to acknowledge individual differences. This fits with social constructionist and constructivist stances in which NT is embedded (Etchison & Kleist, 2000). These posit that there is no one truth but rather there are multiple realities which exist alongside one another (Hoffman, 1990).

NT may therefore offer YP an opportunity to reflect on the different aspects of their experiences with cancer rather than focusing on ‘problem-saturated’ stories that may be dominant in society. For example, it may allow them to consider the importance of being a young person and what this means to them. It may allow for the wider context to be given more of an emphasis, allowing subjects such as transition, school and relationships to be discussed alongside their experiences associated with the cancer. It may also allow them to make links between different aspects of their lives and places the YP as the ‘experts’ in discussing things that they find helpful.

1.8.2. Narrative Interventions and Empirical Research

Although narrative approaches have been used worldwide, there is a lack of research evidencing its utility (Etchison & Kleist, 2000), including with YP. There may be a number of reasons for this. Firstly, NT is embedded in epistemological stances of social constructionism and constructivism, which may be seen as incompatible with certain research methods, such as quantitative approaches (Gale, 1993). Secondly, it could be argued that some journals will not publish alternative methodologies to quantitative approaches (Etchison & Kleist, 2000). As a result fewer outcomes studies are available (Neimeyer, 1993).

Nevertheless, there has been some research that has tried to evidence the outcomes of NT and highlight its utility. For example, Epston (2008) wrote a single case study highlighting its potential use with YP and their families. Furthermore, Etchison and Kleist (2000) reviewed the literature on NT in an attempt to summarise the evidence base, acknowledging the limitations of doing so. They highlight the lack of research in this area and that most of the studies they reviewed adopted a qualitative method and focused on individuals’ relationships. Holding these critiques in mind, they reviewed four papers and found that NT can be helpful in empowering a sense of person agency; helping individuals move from describing difficulties on a personal level to an interpersonal level; helping individuals consider multiple perspectives as to what may be contributing to ‘the problem’; and reducing interpersonal difficulties.

In addition, the use of narratives has been researched in the field of nursing, although this research tends to focus on 'problem-saturated' storytelling (Carlick & Biley, 2004; Crogan, Evans & Bendell, 2008; Redshaw et al., 2011). For example, the Beading Project has recently been developed. This project was originally set up by a social worker who worked on an oncology ward in British Columbia. Her son went on a youth camp and returned with a set of beads from which he told his mother the story of his weekend. The social worker took this idea and applied it to the young people she was working with on the ward. She invited them to add a new bead to a piece of thread every time they had a procedure, injection, bad day etc.; for example, a white bead represented chemotherapy. The project was set up with the aim of inviting YP to bead their experiences and create a story of their cancer journey. It also aimed to offer YP "a chance to document and honour their experience in a tangible and visible way" (Stutzer & Gove, 2000, p. 100).

In a recent study evaluating the Beading Project, Baruch (2010) reported that both parents and YP found it useful and enjoyable 'storying' their experiences with cancer using beads. She also found that beading provided parents, YP and clinicians with a space to reflect on and remember the experiences associated with cancer treatment. Furthermore, beading was seen as a communication tool to tell others what they had been through and provided a sense of recognition and accomplishment.

More recently, the head of the psychological services for childhood and adolescent cancer at UCLH piloted the BP with three young men and three young women, collecting feedback from participants, as well as her team's reflections. Both YP's feedback and the clinicians' reflections highlighted that the BP in its current form was too 'problem-saturated' (i.e. it focused solely on the 'difficulties' and 'challenging' experiences of YP's journeys with cancer). One young woman described how she was only able to bead because of the support her clinical nurse specialist had offered her, yet the project in its current form provided no space to hear about the role of significant others. The clinicians also reflected

how a 'problem-saturated' narrative of cancer had taken over and had stopped YP from developing their independence, instead becoming dependent on others.

It was therefore decided that the BP should be adapted to take into consideration the different stories that exist for YP. As a result the BP now incorporates several ideas and principles from NT, such as those used in Ncube's Tree of Life Project (2006). It adopts the principle of hearing alternative stories (Morgan, 2000) – participants are invited to tell both their cancer story and other less dominant stories in their lives (e.g. their hopes and dreams). It also aims to adopt the narrative principle of creating 'rich descriptions' – participants are asked questions embedded within NT to 'thicken' the stories that go with the different beads (Morgan, 2000). The BP also adopts the principle of witnessing – participants are invited to share stories with each bead and others are often asked to reflect on what struck them about the story they have heard.

Those who take part in the BP are invited to choose from a variety of beads and to place these on different strands. Each strand is associated with a part of Ncube's (2006) Tree of Life Project; there is a strand for each of the following:

- Daily activities and what helps them get to keep going (e.g. their hobbies, interests, faith, beliefs).
- Skills and abilities that they use.
- Important people in their lives, past and present, and the gifts and acts of kindness they have received from these people.
- Family story – where they come from, their favourite foods and favourite places to be.
- Hopes, wishes and dreams.
- The medical/cancer story.

The BP is currently offered to YP, aged 13 to 21, at UCLH. Some YP are at UCLH for a long time whilst others come in for just a day or two whilst they have treatments. This creates some difficulties in offering the BP as those who

engage may not always be able to bead all of the different strands. Nonetheless everyone is offered the opportunity to bead.

Taking the above into consideration one could argue that, despite the limited evidence-base, NT may provide a useful context in which to ask YP about their journeys with cancer and factors that influence their experience.

1.9. Unanswered Questions

As may be apparent when reading the introduction, the aims of this study have evolved. Initial ideas focused on the efficacy of NT and the BP and whether YP may find these helpful. However, having discussed the aims of this study in supervision it was felt that a study exploring the efficacy of the NT and the BP would not be suitable for a doctoral thesis. Furthermore, when conducting the literature review it became apparent that there are some broader unanswered questions, which may be more important to focus on in their first instance. This study therefore focused on exploring these unanswered questions.

Firstly, there appear to be inconsistent findings with regard to the psychosocial impact that a diagnosis of cancer and its associated treatment can have on young people. It has been suggested that YP's experiences can be positive, negative or even both (e.g. Smith et al., 1991). Therefore, it could be argued that perhaps research should be focusing on YP's experiences rather than trying to fit them to pre-existing criteria that professionals have developed for their own purposes. However, having reviewed the literature, there appears to be a lack of research into this. This study will therefore explore young people's experiences of having cancer and how a diagnosis and its associated treatment have impacted on them. It will not make assumptions about whether their experiences will have been positive or negative (or both) and will follow participants' lead on this.

Secondly, as discussed earlier, there is some literature highlighting what YP find helpful during their journey with cancer, although there also appears to be a lack

of research exploring this. This study will therefore also aim to investigate this. This will be asked after exploring YP's experiences in order not to influence what participants choose to say about their cancer journey. However it is worth acknowledging that this second question has been influenced by my epistemological stance – this will be discussed in more detail in the method.

In addressing both of these questions it is hoped that themes can be identified which will allow professionals to think about how they can be most helpful and what oncology services for YP should be offering to support their patients.

1.10. Research Questions

This study aims to explore the following questions:

1. What are young peoples' experiences of their journey with cancer?
2. What do YP find helpful during their experiences with cancer?

2. METHODOLOGY AND METHOD

This chapter outlines the study's methodology and method⁶. I begin by outlining my epistemological stance and the project's methodology and method. I reflect on my role as a researcher and how I thought this may be influential. I go on to describe the procedure of the study, giving information about the participants, recruitment and the data collection. Finally I explain how I conducted the analysis and how I planned to evaluate this.

2.1. Epistemological Stance

Epistemology refers to the theory of knowledge, what it is possible to know and the reliability and validity of knowledge (Willig, 2009). An epistemological stance refers to the extent to which the data produced in research can be seen to mirror and reflect reality (Harper, 2012). An understanding of these is essential given that research aims to produce "knowledge about the world that we can claim as valid" (Green & Thorogood, 2010, p. 11). Harper (2012) therefore suggests that it is important to clarify the researcher's epistemological stance and choose a methodology and method that are consistent with this.

This study adopted a critical realist approach, a perspective that lies between realism and relativism. A realist approach suggests that data directly reflects reality and views the world as rule-bound where there are knowable truths to explore. In contrast, a relativist approach posits that truth is constructed and there are many interpretations of the same data (Harper, 2012). A critical realist approach "combines the realist ambition to gain a better understanding of what is 'really' going on in the world with the acknowledgement that the data the researcher gathers may not provide direct access to reality" (Willig, 2009, p. 13). Adopting this approach should allow a focus to be placed on what people say whilst acknowledging the social contexts (e.g. gender, religion, research) from

⁶ Methodology can be defined as the "general approach to studying research topics" (Silverman, 1993, p. 1)" and method can be defined as "a specific research technique" (Silverman, 1993, p. 1).

which individuals speak. It will also allow for more consideration of the potential impacts these contexts may have on how YP make sense of their experiences.

2.2. Methodology

A qualitative approach allows participants' personal and social experiences to be explored (Smith, 2008) rather than measured (Green & Thorogood, 2010) and enables an understanding of young people's experiences (Thompson & Harper, 2012). Furthermore, a qualitative approach can help identify recurring patterns and is seen to "aid in the understanding of natural phenomena [such as cancer] with an emphasis on the meaning, experiences and views of participants" (Al-Busaidi, 2008, p. 11). A qualitative approach also offers a voice to those that have been ostracised (Willig, 2009). This is particularly pertinent given that "Historically research has marginalised the 'voice' of young people" (France, 2004, p.177).

Qualitative research also aims to answer the questions 'what' (e.g. what is going on and what is that like) and 'how' (e.g. how have you experienced that and how have you coped) (Green & Thorogood, 2010). Taking in to consideration the inconsistent findings in the quantitative research and the need for qualitative research with YP, as described in the introduction, this study aimed to explore what young people's experiences were of their journey with cancer and what YP find helpful during their experiences with cancer. Taking both this and the critical realistic epistemological stance into consideration, a qualitative methodology was adopted.

2.3. Method

I considered several approaches when selecting a method (see appendix 2) before deciding to conduct a thematic analysis (TA). TA identifies and analyses patterns of meaning within a data set and aims to organise and describe these in 'rich' detail (Braun & Clarke, 2006). It has also been seen as compatible with a

critical realist epistemological position (Braun & Clarke, 2006); a TA from this perspective acknowledges

the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of 'reality'. (Braun & Clarke, 2006, p. 81)

TA was chosen as it has been seen to fit best with research questions that aim to explore "the specific nature of a given group's conceptualisation of the phenomenon under study" (Joffe, 2012, p. 212). It can also be viewed as a foundational method as it can provide information that will be useful for conducting further research (Braun & Clarke, 2006). This is pertinent given that there is a lack of research broadly exploring YP's experiences and what has influenced this.

Themes identified in TA can be done so either in a 'bottom up' inductive manner or 'top down' deductive manner (Braun & Clarke, 2006). An inductive TA aims to organise and describe the data "without trying to fit it into a pre-existing coding frame" (Braun & Clarke, 2006, p. 83) whilst a deductive TA involves mapping the data onto theoretical areas of interest (Braun & Clarke, 2006). This study adopted a predominately inductive approach as it fitted with the study's exploratory aims and critical realist epistemological stance. However, Joffe (2012) argues that it is important to hold in mind the current literature in order to avoid repeating previous research and highlight new findings. Therefore a combination of inductive-deductive approaches was adopted, with more of an emphasis placed on an inductive approach.

Another decision that needs to be made when conducting a TA is whether themes identified are at a manifest or latent level. Themes at a manifest level (also known as semantic level) refer to things that can be directly observed in the data. In contrast, themes at a latent level refer to the ideas and assumptions that may shape the manifest/semantic level (Boyatzis, 1998; Braun & Clarke, 2006).

Braun and Clarke (2006) argue that themes identified at a manifest level are mostly associated with a realist perspective, whereas themes identified at a latent level are associated with a constructionist perspective. Taking into consideration that TAs often draw on both types of themes (Joffe, 2013) and the critical realistic perspective of this study, both manifest and latent themes were identified.

Joffe (2012) states that a “dual deductive-inductive and latent-manifest set of themes are used together in high-quality qualitative research” (Joffe, 2012, p. 210). Therefore this study adopted this approach to the TA.

2.4. Reflexivity

Green and Thorogood (1999) posit that it is impossible to conduct a study objectively as both the research and the researcher are part of a world in which values and subjectivities are inevitable. It is therefore important for the researcher to acknowledge that his/her values, beliefs and experiences, amongst other factors, may influence the research. These can be considered during the process of reflexivity, which involves the researcher considering how “aspects of their lives...might influence the conduct of the research study” (Runswick-Cole, 2011, p. 91) and how their involvement in the study may influence the outcomes (Nightingale & Cromby, 1999).

I felt that my position as a young, white British, middle-class, male may have influenced my understanding of YP’s experience. Furthermore I wondered whether these identities may have an impact on what was and was not discussed in the interviews. I will discuss my role in the research in more detail in the discussion.

When developing this research project I was aware of my position as a Trainee Clinical Psychologist and that this research was being conducted as part of my training. I was also aware of how my interest in this research had been influenced by my previous experience; I worked in the psychology team from

which the sample was recruited. Again, these will be discussed in more detail in the discussion.

I was also aware when positioning myself that the above reflections may bring about a power dynamic between me and participants, something that Willig (2009) highlights as important. It is exceptionally difficult to remove this dynamic but, in an attempt to minimise it I, used a semi-structured interview schedule and was guided by participants as much as possible in the interviews.

2.5. Selection and Recruitment of Participants

2.5.1. Sample

As described in the introduction, NT may provide a useful context in which to ask YP about their experiences and factors that influence their experiences. It was hypothesised that ‘rich’ descriptions (Morgan, 2000) of YP’s experiences may be accessed by interviewing those who had taken part in a NT intervention. The sample selected for this study therefore comprised those who had taken part in a NT intervention at University College London Hospital (UCLH): *the Beading Project*, as described in the introduction.

The BP is currently offered to YP, aged 13 to 21, at UCLH. Some YP are at UCLH for a long time whilst others come in for just a day or two whilst they have treatments. This creates some difficulties in offering the BP as those who engage may not always be able to bead all of the different strands. Nonetheless everyone is offered the opportunity to bead.

2.5.2. Inclusion Criteria

The inclusion criteria for this study were as follows:

- Aged 13 to 21.
- Diagnosed with and treated for cancer at UCLH.
- Taken part in the BP, whether they had completed all the strands or only some.

- Agreed when completing the BP that they were happy to be contacted to talk about their experiences with cancer and taking part in the BP.

Participants were excluded if they were not fluent in English and/or had a diagnosis of a learning difficulty. The reasoning behind this was to minimise issues of language and understanding during the interview. Participants were also excluded if they had a speech impediment as this made it difficult to transcribe the interviews.

2.5.3. Sample Size

Guest, Bruce & Johnson (2006) state that a minimum of 6 interviews is enough and that data saturation, “the point at which no new information or themes are observed in the data” (p. 59) despite interviewing more participants, occurs at approximately 12 participants. In addition, Boyatzis (1998) argues that the larger the sample size the better as this is likely to increase the researcher’s confidence that the data is “not contaminated by unforeseen forces” (Boyatzis, 1998, p. 15). I therefore aimed to interview as many YP as feasible within the available time frame, aiming to interview a minimum of 6 participants and as close to 12 as possible.

2.5.4. Recruitment

Since the BP was set up, a database of YP who have been offered the opportunity to take part in this project has been collated. Participants were recruited from this database. This database is regularly updated as new participants take part in the project every week.

A member of the clinical team at UCLH searched through the database and contacted potential participants (i.e. those who met the inclusion criteria) to tell them about the study. Potential participants were either contacted whilst at UCLH or they were contacted via telephone. Where a potential participant was under the age of 18 this conversation took place in the presence of a parent/guardian.

During this conversation potential participants (and their parent/guardian where appropriate) were asked if they were interested in taking part in the study or hearing more about it. They were told that if they were interested they would be sent an information sheet with more details and that they should contact me if they were interested in taking part.

If they declared an interest, verbal consent was sought for their contact details to be given to me. I then contacted potential participants (and where appropriate their parent/guardian) to tell them more about the study and to see whether they would be interested in taking part. I went through the relevant information sheet over the phone and gave them an opportunity to ask any questions about the study. If they indicated an interest in participating I explained that I would go through the information sheet with them again on the day of the interview and that I would ask them to sign a consent form.

2.5.5. Participants

The clinical staff at UCLH attempted to contact YP from the database. At the time of writing there were 39 YP on the database, of which 21 were contacted (53.85%). Those contacted were those that had taken part in the BP most recently as it was hypothesised that they were more likely to take part.

Three of these 21 potential participants were excluded: two did not have a diagnosis of cancer and one had a speech impediment. The clinical staff were unable to get hold of one potential participant and four said they were not interested in taking part. I contacted the remaining 13 potential participants, of whom three did not take part; one sadly passed away and two said they felt too unwell and did not want to take part.

Table 1 summarises the demographic details of the 10 participants (77% recruitment rate) that took part in the study.

Table 1: Participant Demographics

<u>Pseudonym</u>	<u>Age</u>	<u>Gender</u>	<u>Ethnicity</u>	<u>Diagnosis</u>	<u>Age at Diagnosis</u>	<u>Type(s) of treatment</u>	<u>Time since most recent treatment</u>	<u>Duration of Interview (minutes)</u>
Grace	17	Female	Black-British	Embryonal Rhabdomyo- sarcoma	15	Radiotherapy Chemotherapy	2 months	53
Becky	15	Female	Black-British	Non-hodgkin's lymphoma	14	Chemotherapy	2 days	61
Eleni	16	Female	Cypriot	Hodgkin's lymphoma	16	Chemotherapy	Currently	53
Hasan	14	Male	Pakistani	Acute lymphoid leukaemia	13	Chemotherapy Blood transfusions Platelet transfusions	Currently	45

<u>Pseudonym</u>	<u>Age</u>	<u>Gender</u>	<u>Ethnicity</u>	<u>Diagnosis</u>	<u>Age at Diagnosis</u>	<u>Type(s) of treatment</u>	<u>Time since most recent treatment</u>	<u>Duration of Interview (minutes)</u>
Karen	18	Female	White British	Ovarian Cancer	18	Chemotherapy Surgery	1 month	63
Lily	21	Female	British Bengali	Non-hodgkin's lymphoma	20	Chemotherapy Hormone injection	3 months	77
Jay	13	Male	British Indian	Hodgkin's lymphoma	13	Chemotherapy	1 month	50
Ahmed	19	Male	British Bangladeshi	Acute myeloid leukaemia	16	Chemotherapy	3 years	69
Emre	14	Male	Other White Mixed Raced	Osteosarcoma	14	Chemotherapy Surgery	9 days	48
Ralph	15	Male	White British	Hodgkin's lymphoma	14	Chemotherapy Radiotherapy	9 days	55

2.5.6. Data Collection - Interview Process

Participants were given the option of where they would like to be interviewed: at their home, at UCLH, at another hospital if they were an inpatient or at the University of East London (UEL). All interviews were conducted in a private room with only the researcher and the young person present. Five interviews were conducted at participants' homes, four were conducted in a clinical room at UCLH and one was conducted at another hospital. The NHS's guide for lone workers (NHS Employers, 2010) was followed to ensure the safety of the researcher.

If participants were under the age of 18 I met with them and a parent/guardian at their preferred location. They were both given the relevant information sheet to read and an opportunity to ask any questions. If they were both happy for the young person to take part then their parent/guardian was asked to sign a consent form and the young person was asked to sign an assent form. If participants were over the age of 18 I met with them alone and they were given the appropriate information sheet and consent form to sign.

There was an information sheet for participants under the age of 18 (see appendix 3), an information sheet for the parent/guardian of participants under the age of 18 (see appendix 4) and an information sheet for participants over the age of 18 (see appendix 5). There was also an assent form for participants under the age of 18 (see appendix 6), a consent form for the parent/guardian of participants under the age of 18 (see appendix 7) and consent form for participants over the age of 18 (see appendix 8).

Once the consent/assent forms had been completed, demographic details were collated (see appendix 9). When necessary, I asked the parent/guardian to leave and conducted a one-to-one semi-structured interview with the young person. The interviews were guided by an interview schedule, which consisted of several open ended questions that were influenced by my research aims (see appendix 10). Interviews lasted on average 57.4 minutes (range: 45-77 minutes, s.d.: 10.02 minutes).

At the end of each interview, I explained to participants that they could contact me if they would like a summary of the results. At the time of writing no participants had requested this.

2.5.7. Resources

Interviews were recorded using a digital voice recorder; this was placed in view of the participants. Participants were made aware of this in the information sheet and gave consent for the interviews to be recorded. Once completed, interviews were transcribed using a computer and a foot pedal.

2.6. Ethical Issues

2.6.1. Ethical Approval

The study was given ethical approval by UEL (see appendix 11), an NHS Research Ethics Committee (see appendix 12) and the local Research and Development Office (see appendix 13). Subsequently, I submitted an application to change the title of the study and this was approved (see appendix 14)⁷.

2.6.2. Consent

Before signing a consent/assent form, participants (and their parent/guardian where appropriate) had an opportunity to read through the relevant information sheet. They were also able to ask any questions and discuss their rights (e.g. to withdraw from the study or terminate the interview).

2.6.3. Confidentiality and Anonymity

I acted in accordance with the Data Protection Act (Department of Health, 1998) in order to ensure confidentiality and anonymity. These were also explained to participants verbally, as well as outlined in the information sheets and consent forms.

⁷ This explains why the titles in some of the documents in the appendices are different to that of the study.

I was the only person to collect the data and transcribe the interviews. All data was anonymised and participants were given a pseudonym and a participant number to ensure this. These were subsequently used when transcribing and all identifying details in interviews were changed (e.g. family names, location etc.).

The only identifiable data were the consent forms, which were kept separate from the data in a locked filing cabinet. All other data, such as the interview recordings, transcripts and the write up of the study, were kept on a computer requiring a password at log-in.

After examination of the project, identifiable information (i.e. consent forms and recordings of the interviews) will be destroyed and anonymised transcripts will be kept securely for a period of five years.

2.6.4. Further Support

Although no adverse effects were anticipated as a consequence of taking part in the study, the information sheets highlighted that participants could contact the Teenage Cancer Trust should they wish to seek further support. In addition, if a participant requested further support or I was concerned about them I was able to inform the head of the psychological services for childhood and adolescent cancer at UCLH. This was discussed with participants in the post-interview debrief, although none requested this.

2.7. Data analysis

2.7.1. Transcription

Wilkson (2008) posits that transcription can be seen as the first step of analysis and that, if done thoroughly, can facilitate the next steps. However, there are different ways for interviews to be transcribed (Willig, 2009).

Interviews were transcribed at a semantic level only, with a focus placed on what was said rather than the way in which it was said (e.g., tone, emphasis etc.). The transcription conventions used for this study, adapted from Parker (2005), are

shown in appendix 15. In order to be as thorough as possible I listened to the interviews again after transcription (Parker, 2005).

2.7.2. The Process of Thematic Analysis (TA)

Braun and Clarke's (2006) guidelines for conducting TA were employed. They suggest that the researcher follows a recursive process through the following steps:

2.7.2.1. Familiarity with data

This process began during data collection (I made notes during the interviews to aid transcription) and continued whilst transcribing. Having completed this I read through each interview several times "in an active way" (Braun & Clarke, 2006, p. 87) to search for meanings and patterns and began to make notes in the margins of the transcripts (see appendix 16 for an example).

2.7.2.2. Generating initial codes

I then identified features of the data that I found interesting (Braun & Clarke, 2006). These are known as codes, which can be defined as "the most basic segment, or element, of raw data or information that can be assessed in a meaningful way" (Boyatzis, 1998, p. 63).

Once familiar with data I re-read each transcript and my notes several times to establish as many potential themes as possible (Braun & Clarke, 2006). This allowed me to create a list of codes, which were collated in an electronic codebook (see appendix 17); this included extracts that were relevant to each code (see appendix 18 for an example of coded extracts). Some extracts were used for more than one code and all extracts were referenced using pseudonym and line number. Extracts also included surrounding data in order to preserve the context (Boyatzis, 1998).

2.7.2.3. Search for themes

The next process involved organising the codes into broader provisional themes; these were organised visually using spider diagrams (see appendix 19). When

creating themes I thought about “the relationship between codes, between themes, and between different levels of themes (e.g. main overarching themes and sub-themes within them)” (Braun & Clarke, 2006, pp. 89-90). Some codes later became themes whilst others were collapsed into other themes.

2.7.2.4. Review of the initial thematic map

The first part of this process involved ensuring that themes were heterogeneous and that codes within themes were homogenous (Patton, 1990). I re-read the extracts within each theme to ensure that they all related to the identified themes. I then reviewed the different themes and their extracts to ensure they were distinctive. This led to themes being merged, split and newly identified (Braun & Clarke, 2006), producing ‘Thematic Map 1 (see appendix 20). Having produced ‘Thematic Map 1’ the five themes were collapsed into four main themes and eleven sub-ordinate themes. Some were also renamed to better represent the data (see ‘Thematic Map 2’ in appendix 21)

I then re-read the entire data set in order to consider the validity of the themes in relation to the transcripts (Braun & Clarke, 2006). This also allowed me to identify any extracts that had been missed at an earlier stage of coding and consider the names of themes. As shown in ‘Thematic Map 3’ (see appendix 22) I felt that the sub-ordinate themes under ‘feeling better’ could be moved into ‘managing cancer’ and ‘the impact of cancer on individual’. Themes were also renamed, using quotes where possible, to try and better represent the data. ‘Thematic Map 4’ (see appendix 23), the final map, shows how I rearranged, submerged and renamed themes as I felt this reflected the data better. For example, having re-read the data I felt that ‘physical impact’, ‘lifestyle’, ‘image’ and ‘restrictions’ could be submerged under a newly titled theme ‘it’s not exactly like normal’. I also felt that ‘distraction’ could be submerged into ‘personal support networks’ and ‘professional support’ and that the themes regarding context could be submerged. In addition, it seemed that ‘focusing on the positive and the future’ was too narrow a title for the theme as it missed out of some of the data; I therefore renamed it ‘you just deal with it’.

2.7.2.5. Defining and naming themes

This process involved identifying aspects of the data that each theme and subordinate theme captured, what was interesting about them and why. I considered the story that each theme told to help me define them. I also considered the extent to which each theme related to the research aims to ensure they did not overlap (see appendix 24).

2.7.2.6. Producing the report:

The results section aims to provide a precise and coherent summary of the data, “within and across themes” (Braun & Clarke, 2006, p. 93). Numerous data extracts are given to illustrate themes and to invite the reader to evaluate whether the themes and quotes are reflective of the story being told about the data.

2.7.3. Presentation of Data Extracts

In the results and discussion participants are referred to using their pseudonym and the researcher is referred to as ‘Ben’. I also included how many participants reported certain themes; this varies from broad categories, such as ‘some’ or ‘several’, to a specific number of participants. The rationale behind this is to highlight to the reader the differing responses rather than to provide a quantification of the data.

2.8. Evaluating Qualitative Research

It has become increasingly important to evaluate qualitative research in order to address questions about scientific value (Willig, 2009), although this is difficult to do using standardised assessments. This may be due to the philosophical and epistemological stances associated with this type of research. It may also be due to the flexible nature and the lack of methodological consistency used across qualitative research (Spencer & Ritchie, 2012). Nevertheless, Spencer and Ritchie (2012) propose some guiding principles to evaluate qualitative research: contribution, credibility and rigour (see appendix 25 for more detail). These guidelines were used for this study and will be re-visited in the discussion.

3. RESULTS

Having conducted a TA, three super-ordinate themes and six sub-ordinate themes were identified, as shown in table 2 and appendix 23.

Table 2: Super-Ordinate and Sub-Ordinate Themes

3.1. “It’s been up and down”	3.1.1. “It was mainly positive”
	3.1.2. “There are so many different emotions attached to it”
	3.1.3. “It’s not exactly like normal”
3.2. “I have to get through it”	3.2.1. Personal support network
	3.2.2. Professional support
	3.2.3. “You just deal with it”
3.3. Impact on the wider system	

3.1. “It’s Been Up and Down”

This theme explores the varied experiences of living with cancer and the ways in which it can impact young people. It encompasses three sub-ordinate themes: ‘it was mainly positive’ illustrates how YP had had positive experiences in their journey with cancer; ‘there are so many different emotions attached to it’ demonstrates the way cancer can make YP feel; and ‘it’s not exactly like normal’ highlights how cancer brings about change in a young person’s life.

3.1.1 “It Was Mainly Positive”

This sub-ordinate theme illustrates the positive aspects of YP’s experiences, emphasising that having cancer is not only negative but that it also provides young people with opportunities to develop. Throughout the interviews participants spoke about how they had grown or changed, how they had more appreciation for life and how they had had new opportunities.

At the beginning of my interview with Ralph he told me that there were both positive and negative aspects to his experience with cancer. Ralph was quick to share that he had met lots of famous people whilst unwell and that this had been a positive experience. He also highlighted how cancer had been a “life changing experience” (Ralph, line 9665) and seemed to suggest that this was a result of both the positive and negative aspects.

Ben: If we could start just really broadly [Ralph: yeh] I’m really interested to hear what your experiences have been like [Ralph: um] with cancer.

Ralph: Varied I guess. I mean there’s been good and there’s been bad, because of course there would be. Um like last, well it would have been a couple of, two weeks ago, like we were up at hospital and I met Prince Charles which is a pretty [Ben: wow], you know, pretty big thing. And I just thought that was a high point. (9649-9658)

Other participants also explained that their cancer experience had provided them with new opportunities. For example, Eleni spoke about how she had had the opportunity to start knitting, a hobby that she now enjoyed. Similarly, Becky told me how she had found new hobbies, which had become “passions” (line 1410). This illustrates how YP spoke not just about the opportunities that cancer had given them but that these were things that they would take forward.

Becky: I gained new passions like beading, making bracelets and, you know, even arts, more arts and crafts stuff and painting. (1410-1413)

Most participants highlighted that they had more appreciation for life and were stronger as a result of their experiences. For some this was about making commitments towards their future. For example, Grace spoke about how she wanted to help other people and that she now had the opportunity to do anything she wanted.

Ben: Are there other ways in which having cancer has impacted on the way in which you think about the future?

Grace: Um not really but I think I take () life um, I appreciate it a bit more, a lot more () because I still have kind of the opportunity to do () anything. (453-458)

Similarly, Lily spoke about her appreciation for life and how her experiences had made her stronger. In the extract below she illustrates how having a lack of choice and control led her to become more ambitious and had “driven” (line 6565) her to achieve her dreams in life, such as completing university. She also highlights other ways in which her experiences will influence her future when describing how her experiences had provided her with new opportunities and inspirations, such as being more involved with charities and fundraising.

Lily: it's driven me stronger cos now like I need to, I know I like, I've got, obviously after this yeh I've got another year in university left. But I was like 'I'm definitely going to do that and I want to do another course as well'. And it's made me like, my dad's like, it's, since I've been back to work, well I did like a charity, on the 24th October we did this charity event at work. At my work we did this um we had, you know the tea, charity tea day, we had that, but we had in October [Lily laughs], really late. And they did that for me at my work and we raised like 500 and, I think we raised like 560 pounds for the centre where I was treated [Ben: mm]. So I was like, I'm more into charities. Um and I was like, so it's driven me, it's driven me a bit stronger towards other things. (6550-6565)

Ahmed also spoke about how he had become stronger and more mature in the context of having no control and/or choice whilst he was unwell. However, he seemed to focus on how this had increased his desire for autonomy and made him more focused on making “good” decisions (line 8259), rather than achieving things in the future. Furthermore, when talking about being stronger he made reference to how he had become more resilient as a result of his experiences with cancer, which was also highlighted by several other participants.

Ahmed: since I had cancer and all that, it's just made me appreciate that life and think much more stronger [Ben: mm]. Never ever let anyone put you off, put you down because the only thing we can do is, we can't have anyone else ruling our life and telling us what to do and all that. We only can like make choices in our life that are going to be good for us. But you, you speak more open minded, all that, that's what it did to me after I came out of hospital. It just made me think more maturely. (8252-8261)

3.1.2. "There Are So Many Different Emotions Attached To It"

This sub-ordinate theme illustrates the "many different emotions" associated with cancer (Becky, line 1874). Participants spoke about the variety of emotions that they had experienced throughout their journey and how they continued to do so. They also highlighted the contexts in which they had experienced these.

Most participants spoke about the emotional impact of hearing their diagnosis. Several explained that they were worried how they would tell others when they were first diagnosed, discussed more under 'impact on wider system'. Most participants also referred to the immediate impact their diagnosis had had on them. Some referred to this as "quite shocking" (Emre, line 9042) and explained how it was an isolating experience. Many explained that hearing the news had brought about hopelessness and that it put their lives on hold. For example, when speaking about when she was diagnosed Lily said:

Lily: I just burst out crying. And then I was like 'oh my god' cos I had that fear of cancer but I never knew I'd have it cos I thought 'I'm too young to have it' [Ben: mm] cos I was only 20. And I just, I remember crying...I thought to myself 'that's it, my life is over'. Like I was doing, I was in the middle of doing my degree, like I can't sit my exams now. I was, I was in my second year of university and I was like I can't sit my Januar-, my May exams. I was like 'oh crap, I'm going to be a year behind. I've got this, what's going to happen?' Like all this was going through my head. Oh my god, the one thing that kept going through my head was 'how the hell do I

tell my parents? How the, on earth, do I ring my dad and just say it to my dad?' Like 'how do I tell my parents? What's it like?' And then like it did cross my mind that I'm gonna like what, what's the side effects were [Ben: mm]. It just crossed my mind that my life was over. Like everything I do with my life is over. (5319-5344)

In contrast, other respondents reacted differently to hearing their diagnosis, suggesting that it had not been a negative experience; Karen described feeling "lucky" (line 4050) that she was alive and Jay explained that he was surprised to live as long as he had. Eleni also said that she felt "relief" (line 2069) when they worked out what was wrong.

The extract above also illustrates how several participants referred to the unpredictability of the future. Similarly, Jay and Lily spoke about how they were worried about whether their hair or teeth, respectively, would be affected in the future. Ralph and Emre spoke about their concern about activities they may be able to do in the future, such as sport. Karen and Hasan reported feeling uncertain and/or worried about their health and the risk of relapse.

Ben: is it helpful to think about them [aspirations] or to think about the future?

Emre: To be honest some of it can make you quite nervous. Like () even though I know I'm probably gonna catch up with most of my school work quite quickly cos they're sending me work and I've () caught up with a fair bit of it, I've been studying while I've been in hospital or at home, you sort of think 'eew next year's going to be a bit difficult maybe'. (9571-9577)

Karen: I think when you're going through it, it's harder to talk about it than when you're not, when you've got the all clear [Ben: mm]. Cos you still don't know what's going to happen. (4595-4598)

Many participants also highlighted that they had felt powerless and that their lives had become dominated by illness and medicine. For example, numerous

participants referred to how they had to be in hospital and emphasised the impact this had had on them, as exemplified by Grace.

Grace: when you're in hospital and you're around people who are sick and you're sick yourself, you don't feel that great, like you're not particularly happy or excited about life. (286-289)

Other participants spoke about the emotional impact of having to have various tests and treatments. Lily described several times throughout the interview how she was scared of needles, yet needed to have several injections. Ralph explained that he had not been hospital before his cancer and that having to have many different scans and treatments were "scary" (line 10512).

Ralph: before I'd gone in really I'd never really done anything major. I'd never really broken a bone, I'd never done a-, so I hadn't really had any experience of hospitals properly, which was, I think for me, then being straight in having blood tests every single day, being stuck in an MRI scanner for an hour and a half, that was all just rea-, things that were new to me [Ben: mm] and all, all quite scary. (10505-10512)

The extracts evidencing this theme thus far illustrate how cancer had an emotional impact on YP. Several participants also emphasised how they had had to continually adjust during their journey with cancer and the emotional impact this had on them. For example, Lily's extract earlier highlights how she spoke about adjusting her expectations when hearing her diagnosis and how she was unsure about completing her degree. Later in her interview she told me how she had had to continue to adjust as she was wearing a wig.

Lily: even now I do have moments when I feel really depressed. That's when I don't have this [referring to her wig] on because, because it gets to me because I don't have hair. Well I do I have hair but it's like baby. But like now I'm sort of more used to it now. (6544-6548)

At the end of this extract Lily illustrates how most participants felt that cancer had less of an emotional impact over time. Several participants spoke about the hardest part of their experiences being at the beginning and that they got used to it with time – this is discussed further under ‘you just deal with it’.

3.1.3. “It’s Not Exactly Like Normal”

This sub-ordinate theme highlights that cancer can change the way YP live their lives and what they are and are not able to do. Participants often referred to the word ‘normal’, suggesting that this is how they used to be and cancer had, at least for a period of time, changed this.

All participants described how cancer had impacted on them physically and how this had brought about a change. For example, most participants explained that they had experienced some form of pain during their journey with cancer and spoke about how this had led to their life being ‘different’. In the extract below, Karen describes the pain related to her tumour and the implications of this and taking strong medication.

Karen: I had constant pain relief cos I was in that much pain. But I had a number of pain killers. I’d be on morphine and I’d be on paracetamol and I’d be on another pain killer and tablet pain killers. So, yeh.

Ben: And was that helpful? Did they help?

Karen: Um it did help eventually but I had like quite a long time when I was in pain. Cos I was just the size of the tumour () they couldn’t help me being in pain [Ben: mm]. Even the morphine couldn’t stop it. I was just on my way out basically. But it did eventually start working and I stopped getting pain.

Ben: And was the pain localised to where the tumour was or was it all over?

Karen: Ooo the pain () it was, yeh where the tum-, where, most of the time where the tumour was. And it was just such an excruciating pain. You can’t move. You don’t want anyone to talk to you. You can’t walk. It’s horrible. It’s horrible. (4213-4232)

In addition, almost all participants spoke about the pain in relation to treatment they were having and how this brought about change. For example, when Jay spoke about his chemotherapy, he said:

Jay: the treatment was kind of painful as well as kind of funny. Cos I thought like I was, I had a line and I had been stuck to a machine, yeh. And I was like, felt like I was being part of the actual room.

Ben: And it felt like part of the room?

Jay: Yeh cos I was plugged to a machine. So, and the side effects as well, that was extremely painful because I am not, I couldn't actually do the stuff I wanted to do because I couldn't actually even get up for a lot because I was in extreme leg pain and extreme back pain. So that was, so that didn't help a lot. (7036-7047)

The contrast in these two extracts serves to highlight participants' differing experiences, with some reporting the physical impacts cancer had as "horrible" (Karen, line 4175) and "dreadful" (Ahmed, line 7960) whilst others were able to view it as "funny" (Jay, line 7037). These extracts also illustrate that for some the physical impacts were so extreme that they required regular strong medication and prevented 'normal' interactions. In contrast, others described it as more of inconvenience, albeit an unpleasant one, as they were not able to do the things they wanted to do. Nevertheless, all participants spoke about how the physical implications of cancer and its associated treatment brought about change.

Most participants also compared themselves to their peers and to what they were able to do in the past, such as school and sport. This served to emphasise how their lives had become 'different'. It also highlighted the sense of loss that most participants seemed to experience. For example, six participants spoke about how they had not been able to complete their exams and/or how their education had been impacted. Other participants spoke about feeling "prisoned" (Lily, line 6430) and "stuck" (Hasan, line 3025) in hospital or at home, as exemplified by below.

Hasan: there was stuff to do but it was just like, not like, they wasn't like, anything like real life. Like cos like real life you can go everywhere, you can do everything, yeh. In the hospital you were stuck. Like you have to wait for stuff. You can't do anything with, you can do stuff by yourself but you can't do everything. And it's kind of hard. (3022-3028)

In this extract, Hasan also highlights how most participants felt that their experiences had made them more dependent on others and have to ask for more help during a time in their lives when they were trying to become more independent. This change in relationship also served to emphasise how having cancer had made their lives 'different'.

However, some participants were unsure whether they wanted to be independent whilst living with cancer and seemed to accept that this may be an inevitable change that may be important to accept. For example, when Karen spoke about wanting people to go away when she felt ill she said:

Karen: sometimes they'd walk out, my dad would walk out or something and I'd realise I need a drink or I, I want to eat something or I can't reach my phone that I left, that I got my dad to put on the side. So I'd just sit there waiting for them to come back [Karen laughs]. So yeh that was a problem...You'd, I'd, you'd tell them to go away and then you'd think damn I need you though. You don't want them there but you have to have them there. You need them there. It's not a case of what you want, it's what you need. (4444-4458)

Numerous participants also spoke about how cancer had made them feel weak and unable to do certain things as a result of feeling too ill. For example, Becky explained how she did not understand why there was a chair in the shower when she first arrived in hospital but later realised that she would have to use this. She spoke about how this chair and being neutropenic were markers for her difference.

Ben: Were there other ways in which you, it had an impact on you?

Becky: Well as I said earlier like, stuff like, realising like I'd have to use the chair in the shower () even though I've always sort of been like 'phugh I'm not gonna have to use that'. And then becoming neutropenic and being =

Ben: Can you, sorry can you explain what that is to me, I'm not sure.

Becky: Neutropenic is when you are, your white blood cells have gone so you're, you're quite prone to anything. So if you coughed and you had () something in the cough, as in like you had influenza or whatever and I didn't have my white blood cells, I could catch that really easily. (1954-1968)

The majority of participants also made reference to how cancer and its associated treatments had made them either feel and/or look 'different' in comparison to a time before cancer. Some participants, such as Lily and Karen, referred to how they looked different having lost hair and/or being in a wheelchair. Others told me that they noticed that people treated them differently.

Lily: my hair started falling out in clumps, like in chunks. Like not like, it wouldn't fall out in one or 2 strands, it used to fall out in like this [Lily shows clumps of hair]. It was falling so badly, like it wasn't just, I'd touch it and it would fall out. And the worst was, you know when you go to sleep and you know your head obviously rolls around on your pillow. I'd wake up in the morning and, you know, there would be a huge hair ball, like a cat hair ball, on the pillow. I'd be like freaking out. It was getting so depressing. (6080-6090)

Karen: when you're in a wheelchair, people tend to stare at you and obviously because I had no hair as well they stared more. That was hard as well. From being someone that was just normal in this society and then, I don't know, it's just really, really different. (3915-3919)

Although most participants spoke about being and/or looking different and being treated differently as “weird” (Ralph, line 10166) or “bad” (Lily, line 5096), a couple of participants spoke about how they got used to this and accepted that it was a short-term experience. When speaking about how his family had been supportive, discussed further in ‘personal support networks’, Jay told me that he had noticed that he had been treated differently since being diagnosed with cancer. Although he begins by stating that this was a bad thing, he highlights how it also had its benefits as it meant that he was excused from some of his ‘normal’ roles and responsibilities.

Jay: the only bad thing that I felt about that was they were treating me di-, a bit different. Cos if they know that I was kind of weaker so they let me do what I want as well. Like mostly, mostly um I would actually watch tv but then they would interrupt and I, and I would usually let them watch but they actually let me watch for a change. I felt a bit, I actually felt quite good and bad because, good because I’m, I could keep watching what I was watching and bad about um I wasn’t actually being treated normally.

Ben: Mm. What was that like? I mean it sounds like it was good and bad. Um the positives that you got to watch whatever you wanted to watch but I’m interested in this idea of being treated differently [Jay: mm]. Can you tell me more about that?

Jay: Like usually um throughout it, they would usually nag me about doing studying and everything. Now they just let me chill out mostly, yeh, which I felt was I felt was kind of good and bad cos yeh I didn’t really like study that much so I could just do whatever I wanted [Ben: mm] and bad because usually it’s not right, like, I felt that it wasn’t normal for me to actually do that. (7449-7472)

It is also worth noting that some participants reported how cancer made them feel ‘different’ and could continue to do so in the future. For example, Grace told me how cancer had affected what she was able to do in the past.

Grace: the chemo had made me really tired. And on top of that I tore a muscle () and I couldn't walk properly and I was in a wheelchair () and I couldn't walk um long distances. I could walk for about 2 minutes and I'd get really tired and have to sit down for about an hour or I'd fall asleep. (149-155)

In contrast, Hasan spoke about how cancer continued to impact what he was able to do.

Ben: Are there some things that you are able to do yourself or ()

Hasan: Yeh but some stuff is just too difficult.

Ben: What kind of stuff is too difficult?

Hasan: Like, I don't really like to go out by myself cos, in case I fall over or because most of the time, like times I've gone outside, I've like fallen over. Like I can't pick stuff up that are really heavy. (3117-3124)

3.2. "I Have to Get Through It"

This theme comprises three sub-ordinate themes which highlight how YP manage to "keep going" (Emre, line 9586). It also emphasises that being distracted from being unwell and doing 'normal' activities, amongst other factors, allowed YP to focus on getting better.

3.2.1. Personal Support Networks

When asked what they had found helpful during their experiences with cancer, all ten participants spoke about the support of their personal network. Participants spoke in general about the support from their friends, family and partners. They also spoke about interacting with other YP and gave examples of what their support networks were doing that was helpful.

During all ten interviews I heard about participants' supportive families, although they seemed to vary on how this was helpful. Some participants spoke about how their families had offered practical and emotional support, such as going to

appointments with them or bringing them their possessions. Others described how this was about being brought things that they had missed, such as food. Participants suggested that having homemade food, their possessions and having their families around brought about an element of normality. For example, during my interview with Hasan he told me that his family visiting him every day was helpful; when asked to say a little bit more about that he replied:

Hasan: my auntie used to bring food every day like with my grand-mum and dad. My mum stayed with me at the hospital and that helped as well but, yeh and like yeh. My whole family came: my uncle, my cousins and my brother and sister. They always used to come like every day, come to the hospital. (3460-3466)

Ahmed also spoke about his family bringing him food and highlighted that talking with his family and humour had been helpful when they visited him in hospital as it served to minimise his treatment which may have otherwise been anxiety provoking and/or distressing.

Ben: you specifically talked there about your mum, that she'd bring in food that you liked [Ahmed: yeh] but were there other things that other family members brought in?

Ahmed: They usually just come and just like have a joke around and all that. They used to have to talk and all that and everything. There was times I used to have like, I used to have () I have erm, you used to get blood and all that. And it's transfusion blood. And I used to like just lie down and my sisters used to take the () fun of me like um I'm gonna turn into vampire, having blood and all that and I might bite someone. And like, we used to like make all sorts of jokes and all that. You know I've got this big family of my own and all that. I've got 4 older brothers and 6 sisters. And like they used to like come in big bunch of group and just come and visit me. And all the other nurses used to think what a big family I've got and all that and everything. And yeh, that's what used to keep me happy a lot, just seeing my family around me. (8456-8475)

This extract also highlights how different family members were supportive in different ways. Whilst participants spoke about how their parents had spoken to the doctors, had stayed with them overnight and/or had kept them company during their treatment, they seemed to focus more on activities that they did with their siblings. Participants highlighted that doing activities that they would normally do with their siblings had been important as it helped take their mind off feeling unwell and distracted them from the worry and uncertainty described earlier. For example, Jay told me how playing games consoles with his brother distracted him from being unwell and being in hospital.

Ben: You said there about getting back to the life you had before [Jay: mm]. Was that something you thought about while you were being, while you were having treatment?

Jay: Yeh, as well as all the people supporting me as well. That actually helped me cope throughout the entire thing

Ben: Ok. So the people around you [Jay: yeh]. Were there specific people?

Jay: Mm, no just my parents, some of my, my cousins and yeh, and all, my mum's friend, she actually came as well, for the last chemo. Yeh so she actually helped as well.

Ben: What was helpful about those people?

Jay: Um they kept you, kept you positive and, and they actually kept you occupied as well.

Ben: They kept you occupied? [P10: Yeh.] By doing what?

Jay: Just talking to you um most of the time. Like my brother um we played PS, we played playstation a lot as well. So when I was here actually played playstation with him which was actually kind of fun to pass time. (7072-7093)

Although most of the references to personal support networks were around family, some participants spoke about other people in their lives. For example, Lily spoke about how her boyfriend had been with her when she was first

diagnosed and how he had comforted and listened to her when she had been upset. Similarly, in the extract below, Becky highlights how her friends had been supportive.

Becky: when my friends came to visit at () the hotel⁸ [Becky laughs], when they came to visit, we were there singing karaoke and watching music videos and we was doing dumb stuff and everything and they would keep me up to date with the gossip going on at school and I knew everything that was going on. You know social networking sites and everything like that. Facebook, twitter, bbm. You just, everyone, everyone's talking to you on that too because they want to know what's going with you as well.
(1084-1093)

In this extract Becky highlights how doing activities with her friends that she would have done before cancer had been helpful as it also brought about an element of normality. Some participants, such as Karen, also highlighted how friends had been helpful with practicalities, such as lifts and bringing in clothes and toiletries.

Most participants spoke about interacting with other YP and that this had been helpful at times. Similar to above, participants described doing activities with other YP, such as playing pool or talking, to distract them from feeling unwell. In contrast to family, friends and partners, participants also spoke about how there was a shared understanding with other YP and that this was an important support, as exemplified below.

Ben: you got to meet other people, is that something that's helpful?

Karen: Yeh very helpful because if I said to someone that didn't have cancer 'oh, I'm going to my, are you at your local?' They'd be like 'what you talking about?' That means local hospital because my friends would know that I was on home leave, they'd be like to me, and I'd have an upset

⁸ Becky referred to the hospital as "the hotel" throughout the interview. Her family came up with this name so that she did not feel 'different' and was distracted from the idea of being unwell.

face on my phone or something on my instant messaging and they're like 'oh you at your local?' If I said to someone 'I'm at my local' they wouldn't, they'd be like 'what you talking about?' That means my local hospital. If you got ill or something while we was at home. Just I don't know cancer words, people would be like 'huh, pic line? What's the pic line?' 'That line that goes into your arm'. Stuff like that, it's just you don't have to explain yourself cos they already know. It's easier. (4299-4315)

However, the extent to which participants wanted and/or appreciated their personal support networks varied. Some participants reported there were times where they wanted to be alone. For example, in the extract earlier where Karen spoke about being in pain, she highlights how participants did not always want and/or appreciate their personal support networks when they felt unwell. Several participants suggested that this is because it takes energy to manage interacting with others and sometimes they did not want to be reminded that life goes on outside in "real life" (Hasan, line 3025).

Ralph: sometimes you just want to be on your own, like, I don't know, I don't really, I can't really explain it but it's just that you don't wanna be with other people, you just sort of wanna be left on your own [Ben: mm]. So sometimes when there's a lot of other people around that can be a bit of a problem. (9752-9758)

3.2.3. Professional Support

This sub-ordinate theme highlights YP's varied experience of professional support. Participants spoke about different professionals, highlighting both what they found helpful about their support but also some of the more challenging aspects.

All ten participants spoke about the professional support they received in terms of medical support and treatment. Everyone had been treated with chemotherapy and many had experienced several other treatments. For example, most participants had taken steroids and several different types of medication for the

various side effects. Other participants had had surgery and radiotherapy, amongst other treatments. Participants referred to this medical support as imperative in making them better. Furthermore, some participants spoke about how they felt safe under the care of their medical team, as exemplified by Eleni.

Eleni: when you're having chemo, I mean in this hospital, you're in safe hands. All the nurses know what they're doing and there's exact dosages that you have to get. (2687-2690)

Most participants also spoke about non-medical staff and how they had been supportive. For example, Ahmed spoke about how he met with a psychologist and that this had been helpful in reflecting on his experience. The majority of participants also referred to activities that were available on the ward that were arranged by the staff. They suggested that these activities helped distract them from feeling unwell and brought about a sense of normality. Most participants spoke about how they found the Young Person's Group (run once a week) and the Beading Project helpful as they provided an opportunity to meet other YP and talk about 'normal' subjects rather than cancer. Furthermore, the majority of participants spoke about their activity coordinator who had set up activities that took their minds off their cancer and kept them entertained. For example, when asked about what he had found helpful whilst in hospital, Emre replied:

Emre: It was just like having the good staff and like the activity coordinators be quite friendly and informal. So, like, you could have a chat to them as if you were friends. Um () yeh so nothing specific helped, it was just in general, like, having good staff and quick access to like medication and things if I needed it.

Ben: And you mentioned there the activity coordinators and that you, that you had quite an informal relationship with them [Emre: yup]. What was it that they were doing that was helpful?

Emre: Well um they were sort of coordinating exercise sessions so that you wouldn't get bored. That there was like games and stuff. Um they were like coming to visit occasionally, making sure that I was feeling ok,

making sure that I had everything that I needed. Um what's quite nice is that um one of the activity coordinators knows me quite well so every time I come in the room I have, he has like a laptop set up cos I wasn't bringing in this laptop, the ward have their own laptops, cos I didn't want this to get stolen or anything. So I'd always have like a laptop already set up and like, and that's quite nice. It makes the place feel a bit more homely and like, and you're a bit more entertained. (9322-9346)

All participants also made reference to professional support in terms of communication, both in terms of professionals communicating with them and vice versa. Several felt that communication was an important aspect in solving certain problems. For example, Becky told me that it is important to be honest and open with the staff as you "need their support" (line 1498), in terms of medication and other treatment. Similarly, Emre told me how he found it helpful that staff would check to see how he was feeling.

Becky: nurses and doctors ask you a lot of the time 'how are you feeling today? How are you feeling in yourself', which is the question they love to ask every day. And then maybe just saying 'mm () my bum hurts'. You know, just stuff like that...My mouth hurts, this hurts, that hurts () and then getting the solution for it was just, was just much better than just saying you're fine and not getting any solution for it, isn't it? (1563-1571)

Emre: And the staff constantly checking up on me every so often and quickly responding if I call them is also very helpful to like get problems solved quickly. (9491-9494)

In addition, most participants highlighted the importance of professionals communicating with them about what was going to happen and how long it would take. This seemed to reassure participants and made them feel more in control. This is illustrated in the extract below where Ralph speaks about how things became easier when he knew what to expect.

Ben: so you went for these tests [Ralph: yeh] and then you went into London [Ralph: yeh] and then what happened next?

Ralph: Erm they'd finally worked out what erm I'd got diagnosed with and then they knew like timescales, how long it was going to be, when I was going to be in. They sort of all showed me and mum that. And so me and my mum knew how long this was going to be, how long this would last, how long I would be in hospital, how long I'd be at home. And knowing that, that was the point where it sort of just, you know, became () that everything was, well not going to be alright, but it was gonna, it, it was ok cos we knew what was going on. (10594-10607)

Participants also suggested that it was not only communication by professionals that was helpful, but that the way in which this was done was important. Most participants spoke about the staff positively, describing them as "nice" (Becky, line 18), "friendly" (Grace, line 121) and "helpful" (Hasan, line 3545). For example, when talking about what it was like having cancer, Grace told me about how the staff had been helpful and that she liked the way they had spoken to her.

Grace: sometimes in the hospital they have like, they have a games room and a school room so if I was feeling ok I could there. But I didn't go all the time

Ben: And was that, so I just want to check, is that helpful or not to have those activities in the hospital.

Grace: Yeh, yeh. And the people are nice.

Ben: The people are nice. What is it about the people that, that's nice?

Grace: Um they speak to you. Like, everyone's friendly. Everyone's friendly and () they don't speak to you like you're a patient or like you're ill. You know how um some doctors () er I don't know how to explain it. I think um some doctors will speak to you like you're a patient, like just a group of patients or whatever, but some people will speak to you like you're a person, they'll interact with you as, like in a friendly way. (113-129)

However, this was not reported consistently by all participants and some described how they disliked the way in which they were spoken to by professionals. In the extract below Karen illustrates that she understood that she needed professional support but highlights how participants preferred to be spoken to as young people rather than as patients as this made them feel more supported.

Karen: you'd have like the old school nurses that were really like, very old school: abrupt and to the point. So it made it harder for me to get on with them because I needed someone to be a bit understanding, not just 'I'm here to give you your medication [Ben: mm] so you'll take it on time today cos I'm your nurse'. (3876-3882)

Furthermore, not all participants found communication from staff helpful. For example, Hasan highlighted how it was annoying that staff would ask the same question, even though he did not feel any different.

Hasan: I was sick of people asking questions. You know you had to tell them the same answers. (3071-3072)

Similar to before, participants varied in the extent to which they valued professional support. Although no participants disagreed with needing or wanting support, a few spoke about the impact this had on them. For example, Karen told me about times when she did not want to take her medication or take part in physiotherapy when she felt unwell and would tell staff to go away.

Karen: sometimes I just wouldn't get out of bed, I'd, I woul-, I, for about 3 months I didn't get out of bed. That's why I found it so hard to walk again. And the physiotherapist, I didn't really like her cos I was quite ill when she was more, very 'hi how you doing? Let's get up and let's start walking today'. And I wasn't really, I couldn't have people like that around me cos I was so ill. (3949-3956)

Participants highlighted that they did not always have the energy to interact with others when feeling unwell and/or that they did not want to interact with professionals who had not had the same experience or did not understand what it was like to be a young person.

3.2.3. “You Just Deal With It”

Most participants described how they had managed to “just deal with it” (Hasan, line 3198) when referring to how they responded to the variety of experiences they had had. Participants spoke about adopting this approach to their experience of being unwell, the side effects associated with treatment and the impacts that these had had on them. Furthermore, they highlighted what had made it possible to hold on to this idea at different times.

When talking about their diagnosis and its severity, most participants explained that “things sort of sunk in” (Lily, lines 5655-5656) and they got “used to it” (Ahmed, line 8096) it. This appeared to allow them to notice the difficult aspects of their journey and when they needed support, whilst also allowing them to focus on getting better. It also highlighted how things became easier with time. For example, Hasan spoke about how he had to “just cope with” (line 3278) his diagnosis and when asked to say more, he replied:

Hasan: you can’t completely cope with it. Like sometimes you have to tell somebody, like you did in the Beading Project, like that. But sometimes you just have to get on with life. And like you know it’s gonna go one day but you just have to deal with it for the moment because you know you’re going to be better soon [Ben: mm]. Yeh. (3394-3402)

In addition, nine participants referred to other YP. It seemed that participants managed their experience of being unwell by comparing themselves to others who were “worse off” (Becky, line 1141). For example, Ahmed spoke about his friend from the ward who had passed away and Ralph described others finding it “harder” (line 9872). In the extract below Grace discusses other YP who have had lost limbs and compares herself to their situation.

Grace: there's people that have like lost their limbs and stuff and who have even died and I'm still here and I'm still able to carry on at school and still able to maybe get a job later on and stuff like that. And have more options than some people that are less fortunate. (458-463)

Participants also spoke about how they had managed the side effects of their treatment. For example, when talking about losing his hair, Hasan discussed how this was difficult, explaining that he did not want to shave his head. However, he moved on to talk about how it was something that had to be done and he focused instead on the idea that his hair would grow back.

Hasan: I wasn't really wanting to do it [shave his head] but you know you have to do it, don't you. It's like one of those things, you like, when you, if you leave it patchy and it just doesn't look, it doesn't look normal, basically. I don't think so. So yeh just yeh. I didn't really, I wasn't really wanting to do it but you just have to. Yeh.

Ben: Was that alright or was that or ()

Hasan: It was hard but er you have to do it, don't you. It's one of those things, I mean if you've got cancer...Like you can't get away from it cos you know you've gotta but you can't run away from it basically. You do have to deal with it. You have to cope with it. You just have to realise that you've got it and like deal with it. (3644-3663)

Other participants seemed to manage their experiences of the side effects by viewing them as "quite minor" (Jay, line 6915) and something that they had to accept and deal with. For example, Eleni highlighted how she managed to cope with losing her hair by covering it up and she explained how it did not bother her.

Eleni: the worst thing about having cancer and chemotherapy, like, to a normal teenage girl, the worst thing about this would be losing their hair cos, you know, the way they look. I don't really care. I cover it up and it's fine, it's gonna grow back. I don't care. (2514-2519)

In addition, participants highlighted how they had managed the ways in which cancer had impacted on their lives. The majority of participants highlighted that it had been helpful not to dwell on the impact cancer had had on their education and social lives, as exemplified below.

Ben: you said 'you've just got to keep going'. I'm just wondering how you do that?

Emre: Well I'm kind of a fairly detached person so it's kind of easy for me. If you're very emotional and like sensitive it's not so easy. Personally, like, for some people may see you as devastating or life shattering, like they're missing out on near-, like a year of education and they're not seeing all their friends for so long and it's the end of the world. I personally just see it as like a bit of a bother. So mostly I just get through things as quickly as possible and just leave it at that. Don't dwell too long on some things and I find that helps quite a bit in, you know, coping with side effects. (9173-9186)

Numerous participants also spoke about how they had had "to think 'be positive'" and "be stronger" (Ahmed, lines 8537-8538) as this allowed them to focus on getting better rather focusing on the lifestyle changes and uncertainty it had brought about. In the extract below, Jay illustrates this and how his support networks were also helpful in encouraging this.

Ben: how did you remind yourself of that 'beat it' attitude' or 'tell it who's boss' attitude? How did you keep that in your mind?

Jay: Really, I don't know. I think () yeh I don't actually know, I don't know. I think that just kept me positive as well. I think being positive and that was, I think being positive just made me think like that [Ben: mm]. So yeh. As well as people telling me as well 'be positive'. (7578-7586)

Another approach that five participants mentioned as helpful in dealing with the impact cancer had had on them was keeping calm. Similar to before, participants

highlighted how this enabled them to see that they would get better and focus on factors that may help this. They also said that this had been helpful in taking their mind off some of the physical impacts, such as pain. In the extract below, Ahmed highlights this along with several other factors that participants found helpful in distracting them from the impact of cancer.

Ahmed: by supporting and helping, and all that, and making people happy, that's a stronger p-, person. Being patient, that's what made me a much stronger person. I just stayed patient, stayed calm. And the only thing I was able to say to myself was, oh, I just said 'I will, I won't give up [Ben: mm] on that'. (8335-8341)

Participants also made reference to attitudes that helped manage the emotional impact that cancer had had. For example, several times throughout his interview Jay said that he had to "show it [cancer] really who's boss" (lines 7316-7137). In addition, many participants highlighted that they had had to accept that they were unwell; they reported that this had been helpful as it allowed them to focus on getting through this experience rather than letting it upset them, as illustrated below.

Ben: You, you said that you didn't really think how you spoke about your experience with cancer had changed or that it, you felt it had been the same [Eleni: uh mm]. What, how come, why do you think that is?

Eleni: I think it's just cos I been accepting of it the whole way through and like my attitude towards it hasn't changed really. (2636-2643)

Furthermore, most participants described how they had managed the emotional impact cancer had had on them by focusing on the future and being better. They explained that this had given them more hope and something to look forward to. For example, in the extract below Ralph illustrates how he found it helpful to do this rather than concentrating on being unwell and the implications this had.

Ben: And you went back there into what you were saying before [Ralph: yeh] about that's when you try and look forward to things [Ralph: yeh]. Is looking forward to things particularly helpful then?

Ralph: Yeh I find, I think so, because it's sort of just looking forward to the fac-, the future I guess and when things are going to be a lot better, instead of looking along, a lot at the things that are bad. (10126-10133)

3.3. Impact on the Wider System

This theme illustrates how cancer affected participants' wider systems, how they felt an element of responsibility to deal with this and the impact this had on them. It also emphasises that participants' did not view their experiences as individualistic and were aware that others had been affected too.

Several participants spoke about the impact of cancer on their family, predominantly referring to the emotional impact it had had. Some participants highlighted how the uncertainty around their diagnosis and/or future had affected their family and how this had been difficult to witness, even if they were not concerned themselves. For example, Eleni illustrates below how the uncertainty about her health impacted on her mother before she went to hospital for tests and how this was upsetting for her to see.

Eleni: at night, a few days before I came here, she would kind of like force me to sleep downstairs with her because she wanted to be with me er cos she knew she was going to lose me in a couple, a few days um and I could hear her crying at night. It was sad. (2198-2203)

Most participants also seemed to refer to the emotional impact their diagnosis had had on their family. Furthermore, numerous participants explained how they had responded to their families' emotions and how it was challenging to see how it had impacted on them. For example, Grace described how her parents were more upset than her when she was diagnosed and how she felt as if she had had

to support them. Similarly, Lily explained how her diagnosis had affected her father and how it was abnormal for her to see him in this state.

Lily: Dr Smith said that you know 'it's been' um 'confirmed that you have a, a large tissue cell lymphoma... And then my dad is like, I kind of sunk in while Dr Smith was talking to him. Cos I looked to my right and see him weeping and I suddenly burst out crying. And like seeing like my dad, he's like 43, burst out crying is a bit a weird for me. (5472-5484)

Later in the interview, she also explained that she had been worried about telling her mother about her cancer diagnosis; her mother had been previously diagnosed with 'depression' and Lily was concerned about the impact this news would have on her. These examples highlight how participants felt that they needed to support their families when they heard about their diagnoses and the role reversals involved. In addition, they highlight that seeing the impact that their diagnoses had had on their families affected them emotionally too.

Participants also made reference to the way in which cancer had an impact on their families' lifestyles. For example, two participants spoke about how their families had had to move cities to make sure they got the best possible treatment. Other participants spoke about how cancer had impacted their families' day-to-day activities. For example, when asked what kind of impact cancer had on her life, Eleni responded:

Eleni: In school I wasn't taking in any information and, like, my GCSE exams were coming up. And I hadn't slept in 4 months so it was another symptom I think. And I wasn't really doing badly in school. I tried really hard. But it, I think it affected my family life as well cos we were always going to the hospital, like running around to different doctors. And I think it was tiring my family as well cos we didn't know what it was. I think it affected my family life as well cos we were always going to the hospital, like running around to different doctors. (2097-2101)

Furthermore, several participants highlighted the impact their diagnosis had on other people in their lives and how they managed this. For example, most participants spoke about the emotional impact that their diagnoses had had on their friends and several made reference to how they tried to support their friends when they told them the news.

Emre: when I told friends about it, they were quite shocked about it until I told them it wasn't serious and then they just learnt not to take it so badly. (9018-9021)

Ben: So one friend came to visit you [Jay: yeh]. And, so you described that as good. Was that helpful? [Jay: Yeh. Yeh.] How come?

Jay: Um because he, er I told him on the volley [a slang term for a conversation where you reply immediately to each other] that actually that I had it.

Ben: You told him on?

Jay: The volley, on the 12th, actually no the 13th of November. Um so () yeh he actually cried a bit then [Ben: mm]. Yeh so actually I was trying calm him down. (6977-6986)

Ahmed also made reference to how cancer may affect staff and other YP. When talking about how he tried to "be strong" (line 7857), an approach described earlier, he explained that he tried to support those around him as they were affected too.

Ahmed: I was like performing, dancing for the nurses, for the other patients that were quite upset. And I thought the only thing, I don't like seeing other people upset and all that, so I thought, I thought the only way I can make them ups-, er make them happy is dance for them or like sing or entertain them. (7860-7865)

Finally, most participants highlighted that it was not only their diagnosis that impacted their wider system but that it was also the treatment and its associated

side effects. For example, Karen spoke about how her nieces were shocked when they went to visit her. She also explained that their mother, Karen's sister, had not let them visit her for a while as she was concerned about how seeing Karen without hair would affect them. Similarly, Becky spoke about what her friends saw whilst visiting her in hospital and she appears to touch upon how this may have been difficult for them to see.

Becky: I mean honestly the things my friends had seen, when they came to visit me at the hospital, () things like even just seeing me in the toilet, was a lot, you know, for a few of your friends. Because your friends don't normally see you in that aspect. (1794-1799)

4.0. DISCUSSION

This chapter summarises and evaluates the results of the study in relation to the research questions and the literature. It then acknowledges the study's limitations and my role in the project, before considering the implications of the findings.

4.1. Summary of Findings

The study aimed to investigate (a) young peoples' experiences of their journey with cancer and (b) what they find helpful during their experiences. This section summarises the results in relation to these research questions.

The first research question was answered predominantly by the super-ordinate theme "it's been up and down" (Lily, line 6256). This theme highlights how YP had mixed experiences with cancer. Participants described how cancer had been a positive experience and had led to some form of personal growth. They also spoke about the ways in which cancer had impacted on their lives in terms of being and/or feeling 'different' and the range of emotions that had been elicited in a variety contexts.

The second super-ordinate theme, "I'll get through it" (Becky, line 1285) highlights how participants were of the belief that they would get better. This theme addresses the second research question as participants reported a number of factors that they found helpful in their journey with cancer and also what they would have found more helpful. For many this was about being distracted from being unwell and trying to do things that were 'normal'. Participants spoke about getting through their experience with cancer in relation to their personal support networks, professional support and attitudes and coping strategies that they found helpful.

Finally the third super-ordinate theme, 'impact on the wider system', seems to address the first research question. When talking about their experiences with cancer most participants spoke about the impact it had had on their systems. They highlighted how cancer had emotionally impacted on those around them, both when they had had to tell them about their diagnoses and when they came to see them in hospital. In addition, when speaking about the impact cancer had had on those around them, several participants emphasised how this had been difficult to witness and/or that they felt an element of responsibility to support them. This suggests that this is also a part of their experience. This theme may also begin to address the second research question as it may be helpful to consider and acknowledge this when supporting YP.

4.2. Evaluation of the Findings

This section reflects on the three themes identified. It evaluates the results in relation to the current literature and, where possible, outlines any contributions that this study offers. As some developments have been reported, this section will refer to psychological theories, therapeutic ways of working and research with young people and adults diagnosed with and treated for cancer.

4.2.1. "It's Been Up and Down"

This theme highlights that if asked broadly about their experiences, YP will share stories about both positive and negative aspects of their journey with cancer. Although similar findings have been reported (e.g. Engavall et al., 2011), the majority of research appears to focus on one or the other. This theme therefore seems to relate better to NT as it fits with several of its principles. Rather than focusing on one aspect of an experience, NT aims to enable people to consider new possibilities and 'preferred futures', whilst also acknowledging the challenging experiences they are having (Freedman & Combs, 1996). Furthermore, NT posits that there are multiple stories in people's lives, although some may be more dominant (Morgan, 2000). The results seem to fit with both of these NT principles as participants were able to share multiple stories, both positive and negative, about their experiences. In addition, they

reported being able to look towards their future and consider what they had taken from their experiences. Furthermore, given that participants spoke about the positive impact cancer had had, it seems that they were able to tell their stories in ways that made them stronger – another key principle in NT (Freedman & Combs, 1996).

Participants spoke about the positive impact cancer had had on their lives and how it had changed their perspectives. For some participants, cancer had made them focus on what was important to them and they set themselves goals for the future. Similar to previous literature (e.g. Haase & Rostad, 1994), this related to both physical goals, such as aiming to play sport for their university, and mental goals, such as placing more emphasis on helping others and getting involved with charities. Other participants highlighted how cancer had changed their perspective on life as it had made them more resilient and more mature, as previously highlighted in the literature (Bearison, 1991; Enskar et al., 1997; Parry & Chesler, 2005). These findings emphasise the importance of individual difference and serve to further the evidence that if asked broadly about their experiences, YP will speak about the positive impact it has had.

Participants also made reference to how they had more appreciation for life and that they had had new opportunities, such as trying new hobbies and meeting new people, as a result of their experiences with cancer. These findings relate to some of the research in the adult literature regarding Post Traumatic Growth. However, the research in this area with YP is currently limited and this can therefore be seen to develop it.

Another sub-ordinate theme identified by participants, ‘there are so many different emotions attached to it’, highlighted the numerous ways in which cancer had and continues to have an emotional impact on young people. This seems to relate to one of themes identified by Woodgate (2000): ‘cancer hurts in many ways’. It also appears to develop this theme by highlighting some of the ways in which cancer ‘hurts’ and the contexts in which these are experienced, although several of these findings have been previously reported. For example,

participants referred to how they felt when they heard about their diagnoses and how they were worried about how they would tell others. Several participants spoke about how having cancer made them concerned and/or worried about the future, both in terms of relapse and what they may be able to do, as reported by Palmer et al. (2007). The results appear to also relate to the literature highlighting how YP may be concerned about their appearance (i.e. scars and hair loss) in the future (e.g. Hedströma, Skolinb & von Essen, 2004). Other participants explained how they became upset when they were alone and that they felt powerless in relation to their treatment and health, as found by Haase and Rostad (1994) and Hockenberry-Eaton and Minick (1994) respectively. Overall, these findings serve to emphasise the importance of the context in which various emotions were elicited – participants explained why they felt the way they did and told me about what was going on when they experienced different emotions.

This sub-ordinate theme can also be seen to support McDoughall and Tsonis' argument (2009) that more qualitative research is needed to advance theory and model development. The results highlight how qualitative research allows for greater understanding of context rather than considering the emotional impact of cancer on young people in isolation. As Boyle (2011) suggests there is a strong evidence-base illustrating that individuals' experiences will play a major role in their 'wellbeing' and these results serve to emphasise the different contexts in which various emotions are elicited amongst YP.

Similar to the existing literature (e.g. Woodgate, 2000), this study also found that YP may feel like they are not 'normal' and/or are 'different'. As previously reported, most participants highlighted that they felt 'different' as a result of their treatment as it made them tired, weak and lose their hair (Larcombe et al, 1990; Lopez, 2011; McCaffrey, 2006; Woodgate, 2000). Not only do these findings concur with the literature but participants seemed to further it, placing an emphasis on visible markers of difference.

Furthermore, participants spoke about how their experiences had led them to feel 'different' to those around them when referring to how they were not able to do activities similar to others their age. For example, as found in previous research (Haase & Roastad, 1994; Roberts, Turney & Knowles, 1998; Palmer et al., 2007), participants reported not being able to go to school or complete their exams. They also spoke about how they had been treated differently and that they felt dependent on others, which have also been reported in the literature (Haase & Roastad, 1994; Roberts, Turney & Knowles, 1998; Seitz, Besier & Goldbeck, 2009). These findings can therefore be seen to concur with theory of dual stressors, as participants suggested that YP have to juggle the stress of transitioning into adulthood and having cancer (Seitz, Besier & Goldbeck, 2009).

The results also seem to further this theory by highlighting how cancer interrupts YP's transition to adulthood and can, at times, lead to a sense of loss. Participants described some of the 'expected' transitions young people may have to make as they become adults, such as completing school, searching for a job and becoming more independent from their parents, and how these were affected or even interrupted by cancer. The impact these changes had on their development appeared to make YP feel 'different'.

However, this change in developmental pathway and being and/or feeling 'different' was not a negative experience for all participants; a variety of responses were reported emphasising the uniqueness of individuals' experiences with cancer and that they are not all 'problem-saturated'. Some participants reported the benefits of the 'sick role' in terms of having different rights and responsibilities (Parsons, 1951). They appeared to welcome the release from 'normal' tasks and expectations, such as not having to complete housework. In contrast, other participants reported that being 'different' was neither positive nor negative but that they had had to adapt in order to do things as 'normal' as possible. For example, some participants spoke about how they had continued with their education by going to school occasionally or by completing school-work at home and in hospital. This finding is consistent with previous research

highlighting that YP view themselves as ‘normal but may do things differently’ (Woodgate, 2000).

4.2.2 “I’ll Get Through It”

The findings also indicate the importance participants placed on getting through their experiences with cancer. Although there is currently limited research exploring this, as the literature with YP is predominantly ‘problem-saturated’ (Parry & Chesler, 2005), this is consistent with Rechner’s (1990) and Lopez’s research (2011), both of which found that YP focus on getting better and getting through their experiences. Furthermore, this theme appears to relate to Lazarus and Folkman’s stress-coping model (1984)⁹, as participants highlighted the resources that enabled them to get through their journey with cancer.

This theme also fits with the literature on NT, which assumes that, despite alternative stories sometimes being obscured by dominant ‘problem-saturated’ discourses, they still exist (White & Epston, 1990). In contrast to the majority of research which focuses on individuals’ experiences, this study helps, at least in part, to understand some of the contexts of YP’s experiences and the contexts in which they were able to focus on getting through their journey with cancer. Most participants referred to contexts related to the BP and Ncube’s Tree of Life Project (2006). For example, all participants told me about how their daily activities had helped them, often when talking about how they did these with people who were important to them. Others told me about themselves as individuals and attitudes they held on to. This can be seen to relate to the strand in the BP on which participants are asked to choose beads that represent their skills and abilities.

The emphasis on alternative stories and contexts also fits with the NT principle of providing people with a ‘safe’ place to discuss their difficult experiences (Yuen, 2007), sometimes referred to as the ‘riverbank position’. The results concur with the idea that it is important to learn about the person aside from their difficulties

⁹ This theory posits that the extent to which one copes in any given situation depends on the balance between internal and external demands and the individual’s resources (Brennan, 2001).

so that they feel 'safer' and more able to talk about their difficulties when this is discussed (Kaseke, 2010).

One factor that YP found helpful when focusing on getting better was their personal support networks. Most participants made reference to their families and friends and how they had been supportive, a finding that is consistent with previous research with children (e.g. Woodgate, 1999) and adolescents (e.g. Decker, 2007). This also fits with Bowlby's theory (1988) of a secure base, which posits that people are at their happiest when they have a secure base to which they may return. In addition, it is consistent with the systemic principle that the wider system can act as a resource to an individual – systemic therapy states that the way in which families function will inevitably impact the well-being of its members. Therefore, family members can be seen as a resource to any given problem (Goldenberg & Goldenberg, 1996).

Not only did participants refer to their personal support networks as supportive but they highlighted what they were doing that was helpful. Most participants made reference to how their personal support networks had distracted them from being unwell. This can be seen to relate to previous research that suggests that it is important to include "normal adolescent pursuits" on wards designed for YP (Hollis & Morgan, 2001, p. 47) as these may provide YP and their personal networks with something to do when YP are visited. Furthermore, participants reported that it was helpful to do 'normal' activities and to be brought things by their support networks that reminded them of their 'normal' life, such as food. These findings fit with the literature emphasising YP's desire to return to 'normality' (e.g. Rechner, 1990). They also appear to further it by highlighting how YP's support networks can play a role in this.

These findings also emphasise the importance of wards being tailored towards young people and their stage of development. For example, participants made reference to activities that they found helpful to do with their personal support networks (e.g, playstation, gossiping) and how these enabled them to maintain relationships and friendships in the context of having to stay in hospital for long

periods of time. This highlights the importance of ensuring that wards are adjusted to accommodate young people, with activities and common areas where young people can continue to do activities that they enjoy outside of hospital.

In addition, most participants made references to interacting with other YP when talking about what they had found helpful during their journey with cancer. It seemed that having a shared understanding with other YP meant that they felt 'contained' and less isolated. One could argue that this relates to the literature exploring the utility of peer-support groups and how these may influence YP's 'adjustment' as YP seem to act as a support to each another. However, there is limited literature exploring this (Sansom-Daly et al., 2012).

It is important to highlight that the extent to which participants wanted and/or appreciated support from their personal support networks varied, as there were times when participants felt too unwell and wanted to be alone. This emphasises the importance of context in considering whether or not something is helpful to YP (Dallos & Stedman, 2006) and, as explained earlier, the uniqueness of each individual's experience. It also emphasises that although certain factors may be helpful at times, this may not always be the case.

Another sub-ordinate theme identified related to the professional support participants had received throughout their journey with cancer. Similar to previous research which has focused on how YP may become dependent on staff (Seitz, Besier & Goldbeck, 2009), some participants explained that they knew they needed the support of professionals. However, most participants seemed to take a more nuanced and critical approach of their relationships with staff – they spoke more about what staff were doing that was both helpful and unhelpful. Similar to above, they also varied in the extent to which they wanted and/or appreciated this support, depending on how they were feeling. This, again, highlights the importance of context and the inimitability of YP's experiences.

Nevertheless, staff members in general were spoken about in a positive manner and were described as helping YP during some of their more challenging experiences. The majority of participants spoke about how supportive staff had been and how they had helped keep them distracted from their cancer. For example, most participants referred to how their activity coordinator had kept them entertained with activities they enjoyed – this can be seen to add to the limited evidence-base there is for this and similar posts (Bratton et al., 2005; Chambers, 1993; Thomas, 2011). Several participants also highlighted how staff had been supportive by bringing YP together for the Young People's Group and the BP, again suggesting that peer-support groups may be helpful. In addition, participants spoke about the various treatments that had been administered by staff and how this had helped them to get better. This highlights YP's acknowledgement that, although some of the treatments may have brought about negative experiences, in hindsight they were able to see why staff had administered these and that they were imperative in helping them overcome cancer. This can also be seen to relate to previous research highlighting how YP may become dependent on staff (Seitz, Besier & Goldbeck, 2009), as discussed above.

Furthermore, most participants referred to the importance of communication with staff and how it was helpful to receive information about their health and treatment. They highlighted how this had helped resolve problems (e.g. side effects) and how it had helped reduce uncertainty and worry as they felt that they knew what to expect. This appears to further Engvall et al.'s research (2011) by highlighting that receiving information around the time of diagnosis is not only helpful in encouraging a positive outlook later in life but that it can also be helpful during treatment. Furthermore, participants highlighted that communicating information also helped reduce uncertainty and worry and helped increase YP's sense of control.

This study also highlights that the way in which YP were spoken to by staff was important – some participants reported that they did not like the way that staff had spoken to them. It seemed that it was important for participants to be seen as

young people with cancer rather than as cancer patients. Similar to the findings described earlier, this serves to highlight the individuality of YP's experiences and the importance of considering their contexts (Dallos & Stedman, 2006).

These findings also suggest that it may be helpful for staff to reflect on the way in which they communicate and that it is important for staff to get to know the young person, aside from their cancer, perhaps during the early stages of their treatment. This could be done by having 'problem-free' talk with the YP and/or the families and/or offering a space where YP and staff can use the common areas to do different activities (e.g. play pool, watch a film).

Another finding suggests that YP found it helpful to hold onto certain attitudes towards their experiences, such as "you've got to show it who's boss" (Jay, line 7322). Participants seemed to apply this and other similar cognitive strategies (such as having to cope and getting on with things) to hearing about their diagnosis, to their treatment and to the impacts cancer had evoked. This serves to highlight YP's 'natural' resilience that, all too often, seems to be overlooked in the literature.

Participants described a number of ways in which they had been able to maintain these attitudes. They highlighted coping strategies that they felt enabled them to hold on to these ideas, including positivity and optimism, which have previously been seen as helpful in the literature (Maurice-Stam et al. 2009; Wu et al., 2009). Some participants explained that they had been able to focus on getting better by getting used to their experiences, which has also been reported by Woodgate (2000). Others highlighted that they did not view cancer, their treatment or the associated side effects as problematic and that it was something that they would get through. This was also identified by Kameny and Bearison (2002) who suggest that this relates to the psychodynamic theory of defence mechanisms, in particular denial. Similarly, several participants spoke about other YP and made 'downward comparisons' (Festinger, 1954); this seemed to allow them to focus on getting better and reflect on how their circumstances could be worse.

One could argue that the theme 'you just deal with it' suggests that concepts derived from solution-focused therapy might be helpful in working with YP, as participants were able to reflect on their difficult experiences, whilst also discussing their future and how they were going to overcome their difficulties – all of which are key processes in solution focused therapy (Macdonald, 2007). However, there is limited research exploring these concepts and this study therefore develops these ideas.

4.3.2. Impact on the Wider System

The results also emphasise YP's awareness of the ways in which their cancer impacted on those around them. It seemed important for participants to talk about their experiences in the context of their wider systems, rather than discussing them individualistically, as this constituted part of their experience. For example, most participants spoke about the impact cancer had had on their families, a finding that has been widely reported in the literature (e.g. Long & Marsden, 2011). In particular, several participants spoke about how the early stages of their experiences with cancer had had an impact on their families, which is consistent with previous literature that suggests the early stages are often the most disruptive (Freeman, O'Dell & Meola, 2000). They also highlighted the emotional impact of their diagnoses and journeys with cancer on their families, which has similarly been well documented (e.g. Eiser, Eiser & Stride, 2005). One participant spoke about how her father had been with her when she was diagnosed and the emotional impact her diagnosis had had on him. This highlights the emotional impact on fathers, an area that seems to have been overlooked. The research tends to focus on the emotional impact on YP's mothers and families in general. This finding therefore suggests that future research focusing on the impact on fathers may be necessary. Furthermore, this participant spoke about how it was difficult seeing her father visibly upset, something she may not have experienced before. Similar to above, there is a lack of research exploring the impact of seeing others' reactions to their cancer and how this in turn can have an impact on YP.

Several participants commented on the personal impact of seeing their families' reactions to their cancer; they described feeling shocked and distressed seeing their families' responses. This highlights the role reversal experienced by some, with YP having to care for and protect their families. In contrast to the finding above, which highlights how YP felt 'different' and more dependent on those around them, this finding suggests that, despite a diagnosis of cancer, YP may still begin to transition from being a 'dependent child' to an 'independent adult'.

This theme also highlights the emotional impact that their diagnoses had on their friends and the staff caring for them. It also suggests that there were times when it was difficult for others to see them unwell. Both of these appear to be underreported in the literature. For example, although there is some research highlighting the impact that cancer can have on relationships, there is a lack of research exploring the impact of cancer on YP's friends. The results therefore serve to develop the literature and show that the YP's whole system may be affected, again highlighting some of the contexts in which this may happen.

4.3. Limitations

Having summarised the results and considered how they relate to and contribute to the literature, it is important to reflect on some of the limitations of this study.

4.3.1 Sample

Participants' demographics varied in terms of their age, gender and ethnicity. The sample was also heterogeneous with regard to diagnosis, time since diagnosis and time since last treatment. This presents a challenge in generalising these results, although this was not considered problematic as this study focused on the qualitative experiences of YP and factors that influenced these experiences rather than differences between YP.

The composition of the sample could be considered another limitation, as it comprised those who had taken part in the BP at UCLH. It may therefore be that the way in which participants answered questions in the interview may have been

influenced by this. Furthermore, Lavigne and Faier-Routman (1992) suggest that recruiting a sample from a single site may raise the issue of bias because of the characteristics of local services. However, recruiting participants from a London-based tertiary service that takes national and international referrals should have mitigated this.

Participants were excluded from the study if they had a speech impediment and/or a learning difficulty. Although these criteria were adopted in order to minimise issues of understanding, they may have acted to further marginalise certain populations.

Furthermore, in excluding potential participants diagnosed with a learning difficulty I acknowledged, to some extent, the validity of this construct, in that it may have influenced potential participants' ability to communicate. However, it is important to be cautious about an uncritical approach to categorical approaches to intelligence as these can be understood as social constructions rather than 'truths'. At times this felt particularly pertinent in the interviews as I wondered how some of the treatments had impacted on participants' cognitive abilities – a well reported 'late effect' (Palmer, Reddick & Gajjar, 2007).

4.3.2. Data Collection

When organising a time to meet with potential participants, several requested to rearrange their interviews as they were feeling unwell and/or had a hospital appointment. This highlighted the complexity of data collection with this population and the importance of the researcher being flexible.

Although the results have, at least in part, added to the literature, it has been argued that it can be helpful to interview participants more than once as this may allow YP to better engage and feel more comfortable sharing their experiences (Woodgate 2000). Therefore, the results may have been enriched by having several shorter conversations (Graue & Walsh, 1998).

I also wonder whether the location of the interviews influenced the results. Half of the interviews were conducted in hospital or clinical settings where participants met with professionals in relation to their cancer. On reflection, it may be that different results may have been found if I had met with all participants at their homes or in an atmosphere that did not relate to their cancer.

4.3.3. Research Journey

As mentioned in the introduction, the aims of this study evolved over time, so that more emphasis was placed on the experiences of young people with cancer. The rationale behind this was that YP have to deal with 'dual stressors' – cancer and 'normal' stages of development (Seitz, Besier & Goldbeck, 2009). Although this has been reflected in the introduction, in hindsight I think that my interview schedule may not have been adapted sufficiently to take young people's stages of development in to consideration and therefore some of these ideas have not been elicited during the interviews. I think that future research may benefit from placing more of an emphasis on stages of development and how these may or may not be affected by cancer. For example, more emphasis could be placed on developing an identity, school and exploring sexuality.

4.3.4. Analysis

The results were analysed using a critical realist TA, focusing on YP's experiences and how these were influenced by their broader social context. Given that this method is not directly associated with any epistemological stance, I could have conducted a social constructionist TA in order to place more emphasis on how YP's experiences are socially produced (Braun & Clarke, 2006). Alternatively a discourse analysis may have been helpful to generate an understanding of how YP construct their experiences and the impact this may have. Another method that may have been appropriate is an interpretative phenomenological analysis – this may have helped produce a greater understanding into YP's subjective experiences. The focus of different methods is discussed further in appendix 2.

Another limitation is that TA can be seen to organise data in relation to how the researcher and his/her research questions connect with this (Joffe & Yardley, 2004). This is discussed in more detail below.

4.4 The Role of the Researcher

The researcher inevitably plays an integral role in the way in which qualitative research is conducted and reported (Patton, 1990). Parker (2005) posits that there are different stages involved in the process of reflexivity: confessions, positions, theorising and crafting. In order to keep these ideas alive a reflective journal was kept (Andrews, 1996) throughout the study (see appendix 26 for example extracts).

4.4.1. First Person Reflections – Confessions

I would identify myself as having an interest in social constructionist ideas and strength-based therapies, specifically systemic therapies and NT. I think this inevitably influenced my epistemological approach to the study and my research questions. Furthermore I think these interests played a significant role in the development of the themes ‘impact on the wider system’ and ‘I’ll get through it’ and my interpretation of the results.

I also feel that my position as a young, heterosexual, male may have been influential. For example, I was curious about whether participants found it challenging to discuss certain topics, such as whether cancer had affected their sex lives and whether or not they would be able to reproduce. However, it may have been that this was not an experience participants had had or considered, rather than participants not feeling able to share this.

4.4.2 Second Person Reflections - Positions

I previously worked as an Assistant Psychologist in a Child & Adolescent Health Psychology Service, where I began to develop an interest in working with this population. This instigated my interest in how physical illness impacts on the development of young people and how it can affect them. I was encouraged in

this post to work systemically and to be curious about what it was like to be a young person with a physical health problem. I have continued to develop these skills throughout my training and feel that they have inevitably influenced the way in which I approached working with this population and this research.

I also feel that my position as a Trainee Clinical Psychologist may have been influential. Kvale and Brinkman (2009) highlight the potential risk of developing a therapeutic relationship when conducting interviews and I wonder whether at times there was a fine line between my research questions and therapeutic questions. For example, during most interviews I asked participants “what made that possible” (Ben, line 4495) when they were talking about how they had been able to cope or manage their experiences with cancer. It may be that someone who was not receiving teaching on therapeutic ways of working may have conducted the interview differently and/or asked different follow-up questions.

4.4.3. Third Person Reflections – Theorising

Parker (2005) argues that the interactions between the researcher and the interviewees are an essential and valuable part of research and that it is important to reflect on this. I felt I built a good rapport with all participants and this appeared to be exemplified by participants sharing personal stories in what felt like a relatively short amount of time. Furthermore, several participants spoke at the end of their interviews about how they had enjoyed taking part, with some describing it as a helpful experience. For example, Ahmed told me he had found it interesting and helpful to reflect on his experiences. Similarly, at the end of the interview Karen told me she had enjoyed taking part in the study.

4.4.4. Fourth Person Reflections – Crafting

I think the way in which the report has been written has inevitably been influenced by the reflections above. I have aimed to share the reasons why I think I found the results that I did and why they may have been reported in the way they have.

In writing this report, I also became aware of the impact this research had on me, both personally and professionally. I feel it has helped me reflect on my clinical practice and the way I ask certain questions, especially following the transcription process. I also think the results will impact on my clinical practice – this is discussed in more detail below. On a personal level I do not think I had anticipated the emotional impact this study would have on me; there were times where I found it upsetting to hear some of the participants' difficult experiences. Although I have had the clinical experience of working with this population, I feel that this was different to hearing YP's experiences several times (e.g. during the interview and transcription) and then immersing myself in the data when analysing. Nevertheless, as is often the case with my clinical work, I found myself inspired by the YP I met and the ways in which they spoke about their experiences.

4.5 Reviewing the Quality of Qualitative Research

There are different criteria to reviewing the quality of qualitative research and these vary according to methodological preferences (Willig, 2009). However, Spencer and Richie (2012) outline three guiding principles that can be applied to all qualitative research, including the critical realist TA adopted for this study (see appendix 25 for more detail).

4.5.1. Contribution

In order to allow the reader to reflect on the contribution of this study, I presented demographic data in the method. Furthermore, in this chapter I have summarised and evaluated the results and considered how these may relate to the current research. The limitations of the study have also been considered and I discuss below the implications of the findings.

4.5.2. Credibility

To address this issue a thorough transcription process was adopted (see appendix 15). This was done to ensure that the interviews were represented as

accurately as possible. In addition, numerous extracts have been presented to support the arguments made.

Some authors suggest that triangulation¹⁰ is also important to assess a study's credibility. However, given the critical realist approach adopted and the social constructionist ideas this holds in mind, I did not ask anyone else to analyse the data and assess inter-rater reliability. I did, however, share a draft of my analysis chapter and the relevant appendices with my supervisor.

4.5.3. Rigour

Spencer & Richie (2012) suggest that the rigour of a study can be assessed by considering the following:

4.5.3.1. Reflexivity

Although some (e.g. Seale, 1999) believe that it is possible for the researcher to be objective and stand away from their values, Spencer and Richie (2012) argue that this is a challenge for qualitative research studies. They, therefore, refer to the importance of the researcher reflecting on his/her role in the research. This has been addressed in both the method and discussion.

4.5.3.2: Audibility

Spencer and Richie (2012) emphasise the importance of documenting and reporting how and why certain decisions were made. I therefore presented 'the process of TA' in the method. In addition, I outlined in the method how and why several decisions were made when conducting the TA. I have also included several appendices to further evidence this (see appendices 17-24).

4.5.3.3 Defensibility

Spencer and Richie (2012) also argue that it is important to offer clear rationale for why the sample and method were chosen. These have been given in both the introduction and the method. The ethical issues and my epistemological stance

¹⁰ This refers to "a process involving the use of different methods, sources or 'readings' to check the integrity of, or extend, the inferences drawn from the data" (Spencer & Richie, 2012, p. 231).

were also discussed in the method. In addition, the rationale as to why TA was chosen is discussed in the method and then critiqued in this chapter.

4.6. Implications of Findings

4.6.1. Clinical Practice

Given that participants discussed the variety of experiences they had had, both positive and negative, it seems important for clinicians to hold a position of curiosity when working with YP, rather than making the assumption that having cancer will be purely problematic (Morgan, 2000). By holding this position, clinicians may be able to acknowledge that YP may approach their cancer experience differently at various times. There may be times where it may be helpful for clinicians to adopt problem-solving approaches, such as when cancer impacts YP's developmental milestones, resulting in their feeling hopeless and/or 'different'. In contrast, there may also be times when professionals may find it helpful to adopt a narrative approach and 'thicken' the story (Nylund, 2000) to find out more about the positive experiences YP have with cancer.

Furthermore, the variety of experiences reported by participants and the contexts in which these took place highlights the importance of individually tailored psychological formulations (British Psychological Society, 2011; Johnstone, 2006). Boyle (2011) suggests that professionals all too often avoid giving prominence to the role of experiences, instead focusing on a medical model. Placing more of an emphasis on formulations should allow for all experiences to be considered, as well as the individual's contexts, strengths and resources.

Another theme highlighted by participants that may have a clinical implication is that they focused on getting better and how they were able to do this. This finding reflects YP's 'natural' resilience and suggests that clinicians may adopt solution-focused and systemic approaches to capitalise on this. Participants spoke about how they had been able to keep going and how they managed this, suggesting that, for some, a solution-focused approach may be helpful. Others highlighted the importance of their support networks and how they had been a

resource, which can be seen to concur with a systemic approach. Furthermore, participants spoke about professional support and highlighted how this had been both helpful and what would have been more helpful. This finding maps on to the systemic concept of 'relationship to help' (Reder & Fredman, 1996), suggesting that it may sometimes be more helpful to work with staff. Several participants also spoke about cognitive strategies that they had adopted for dealing with their experiences, highlighting the potential value of CBT with this population.

Another theme highlighted by participants was the potential impact cancer can have on their wider system. This suggests, again, that a systemic approach may be helpful. Adopting this approach should allow clinicians to consider 'who wants what from whom' (Reder & Fredman, 1996) rather than assuming YP want and/or need support. This approach should allow the clinician to offer an intervention to the YP and/or their system, depending on who is requesting support.

Overall, it seems that the findings are fitting with several NT principles, as discussed earlier. Furthermore, the results are fitting with the BP, as participants made reference to the strands that YP bead. Throughout the interviews participants spoke about their daily activities, important people in their lives and their cancer. Participants also told me about their families, their skills and abilities and their hopes and dreams. Furthermore, several of the themes identified map on to the strands that YP bead. For example, 'personal support networks' can be seen to relate to important people and 'you just deal with it' can be seen to relate to skills and abilities. Therefore, although not an aim of the study, the findings suggest that NT, in particular the BP, may be a useful intervention for YP as it allows participants to speak about the differing contexts of their lives alongside their cancer experiences. The BP can also be seen to highlight some of the resources that YP may find helpful. However, more research is needed to explore whether the BP is helpful to YP.

4.6.2. Service Level

Given that participants described how communication with staff and the ways in which they were spoken to had influenced their experiences, it seems important

for services to take this into consideration and perhaps emphasise it in staff training. Furthermore, participants felt that doing everyday 'normal' activities was helpful. Both of these findings highlight that more emphasis needs to be placed on differentiating between services for children and young people, as it may be that the latter are not best served by services designed primarily for a younger age-group.

Services should also take into consideration the impact of cancer on the wider system and ensure that they can either offer support and/or signpost those wishing to access further support. This may take the form of support for the whole family affected by cancer, support for family members of YP and/or support for staff. They may also wish to take into consideration that YP found their activity coordinators helpful in distracting them from their cancer, suggesting that they are an essential member of the multidisciplinary team.

4.6.3. Policy Level

The findings suggest that policies should acknowledge the varied experiences YP can have. One could argue that policies should adopt a more strength-based approach as, if asked broadly, YP will speak about both the positive and negative aspects of their experiences. Furthermore, policies should include factors that have helped YP get through their experiences. For example, several participants spoke about how having their families stay with them whilst in hospital was important and this can be implemented in policy.

4.6.4. Future Research

Further research would help explore whether the BP enabled YP to speak about their varied experiences and the contexts in which these took place or whether all YP talk in this manner. Such research would involve conducting the same or a similar project, recruiting participants who had not taken part in the BP or a NT intervention.

This study also suggests that future research may benefit from adopting a longitudinal method and/or from focusing on YP's prospective experiences. This

may allow for greater understanding of YP's journeys, when they are able to adopt different approaches and it may help explore how and when YP feel able to focus on their resources and getting better.

Taking into consideration the theme 'impact on the wider system', it may be important for future research to focus on this. Such research may offer a better understanding of how cancer affects the whole system (i.e. YP, family, staff, friends etc.), as well as how members of the system view its impact on others.

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APPENDICES

Appendix 1 – Search Strategies for the Literature Review

An initial scoping literature search was conducted to identify relevant papers, which were scanned for key words. The key words and how they were paired are shown below:

S1	Cancer	S25	S1 + S5
S2	Psycho-social	S26	S1 + S6
S3	Psycho social	S27	S1 + S7
S4	Psychosocial	S28	S1 + S8
S5	S2 or S3 or S4	S29	S1 + S12
S6	Mood	S30	S1 + S14
S7	Emotion	S31	S1 + S15
S8	Mental health	S32	S1 + S16
S9	Well-being	S33	S1 + S17
S10	Wellbeing	S34	S1 + S18
S11	Well being	S35	S1 + S22
S12	S9 or S10 or S11	S36	S1 + S23
S13	Psychology*	S37	S1 + S24
S14	S12 or S13		
S15	Transition	S38	S25 or S26 or S27 or S28 or
S16	Quality of life		S29 or S30 or S31 or S32 or
S17	Depression		S33 or S34 or S35 or S36 or
S18	Anxiety		S37
S19	Post-trauma*		
S20	Post trauma*	S39	S38 narrowed by age
S21	Posttrauma*		(adolescence: 13-17)
S22	S19 or S20 or S21		
S23	Coping		
S24	Resilienc*		

These were searched for in the following databases: PsychInfo (1806 – present), PsychArticles, MEDLINE and CINAHL.

Using the above strategies 2815 articles were identified. Filters were then used to make the reading more specific to the research project. For example, articles included were those that focused on an adolescent population, although some child and young adult papers were used. Furthermore, meta-analyses and systematic reviews were prioritised over papers reporting on single studies due to the large body of literature. Papers adopting qualitative methods were also prioritised given the nature of this research. Papers were excluded if they focused on medical treatment or were not written in English.

In addition to searching the above database Google Scholar was searched to find individual articles that were relevant.

Psych-info and psych-articles (via EBSCO) literature search

Search number	Search criteria / words	Number of articles
S1	Cancer	43778
S2	Psycho-social	2457
S3	Psycho social	2692
S4	Psychosocial	142872
S5	S2 or S3 or S4	144517
S6	Mood	50376
S7	Emotion	107886
S8	Mental health	363287
S9	Well-being	43980
S10	Wellbeing	4093
S11	Well being	46375
S12	S9 or S10 or S11	48542
S13	psycholog*	1649324

S14	S12 + S13	9814
S15	transition	36878
S16	Quality of life	41226
S17	Depression	173247
S18	Anxiety	149581
S19	Post-trauma*	8146
S20	Post trauma*	8496
S21	Posttrauma*	24883
S22	S19 or S20 or S21	27995
S23	Coping	59153
S24	Resilienc*	11983
S25	Positive	214426
S26	S1 + S5	1712
S27	S1 + S6	184
S28	S1 + S7	124
S29	S1 + S8	214
S30	S1 + S12	360
S31	S1 + S14	95
S32	S1 + S15	77
S33	S1 + S16	2049
S34	S1 + S17	1036
S35	S1 + S18	749
S36	S1 + S22	186
S37	S1 + S23	1152
S38	S1 + S24	38
S39	S1 + S25	565
S40 (articles on psych-info and psych-articles)	S25 or S26 or S27 or S28 or S29 or S30 or S31 or S32 or S33 or S34 or S35 or S36 or S37 or S38 or S39	6835
S41 (articles on psych-info and psych-articles)	S40 narrowed by age (adolescence: 13-17)	479

CINAHL Plus (via EBSCO) literature search

Search number	Search criteria / words	Number of articles
S1	Cancer	150356
S2	Psycho social	876
S3	Psycho-social	824
S4	Psychosocial	253637
S5	S2 or S3 or S4	254088
S6	Mood	9863
S7	Emotion	4226
S8	Mental health	65148
S9	Well-being	19877
S10	Wellbeing	3021
S11	Well being	20859
S12	S9 or S10 or S11	23236
S13	psycholog*	145868
S14	S12 + S13	8871
S15	transition	12927
S16	Quality of life	67793
S17	Depression	72620
S18	Anxiety	37912
S19	Post-trauma*	11692
S20	Post trauma*	11856
S21	Posttrauma*	4680
S22	S19 or S20 or S21	13670
S23	Coping	27907
S24	Resilienc*	2918
S25	Positive	101986
S26	S1 + S5	6274
S27	S1 + S6	123
S28	S1 + S7	30
S29	S1 + S8	126

S30	S1 + S12	369
S31	S1 + S14	63
S32	S1 + S15	135
S33	S1 + S16	3169
S34	S1 + S17	769
S35	S1 + S18	521
S36	S1 + S22	102
S37	S1 + S23	808
S38	S1 + S24	40
S39	S1 + S25	2162
S40 (articles on CINHL Plus)	S25 or S26 or S27 or S28 or S29 or S30 or S31 or S32 or S33 or S34 or S35 or S36 or S37	11655
S39 (articles on CINHL Plus)	S40 narrowed by age (adolescent: 13-18)	830

Medline (via Web of Knowledge) literature search

Search number	Search criteria / words	Number of articles
S1	Cancer	970510
S2	Psycho social or Psycho-social or Psychosocial	56625
S3	Mood	48647
S4	Emotion	52723
S5	Mental health	137333
S6	Well-being or Wellbeing or Well being	133539
S7	Psycholog*	963505
S8	S7 + S8	27888
S9	transition	195462
S10	Quality of life	183809
S11	Depression	248899

S12	Anxiety	132704
S13	Post-trauma* or Post trauma* or Posttrauma*	54194
S14	Coping	45676
S15	Resilienc*	6555
S16	Positive	1005466
S17	S1 + S2	5541
S18	S1 + S3	1811
S19	S1 + S4	1708
S20	S1 + S5	2715
S21	S1 + S6	12028
S22	S1 + S8	2546
S23	S1 + S9	9570
S24	S1 + S10	29967
S25	S1 + S11	7810
S26	S1 + S12	6050
S27	S1 + S13	822
S28	S1 + S14	3879
S29	S1 + S15	198
S30	S1 + S16	36
S31 (articles on Medline)	S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 + S29 + S30	63633
S32 (articles on Medline)	S31 narrowed by age (adolescent)	4369
S33 (articles on Medline)	S33 narrowed by psychology as MeSH heading	2235
S34 (articles on Medline)	S33 narrowed to English only	2097
S35 (articles on Medline)	S34 narrowed by psychology, adverse effects, mortality and secondary as MeSH qualifiers	1578

Appendix 2 – Choosing a Method

I considered several approaches when selecting a method including narrative analysis, interpretative phenomenological analysis, grounded theory, discourse analysis and thematic analysis. I will give some information on each the analyses I considered and why it was or was not chosen.

Narrative Analysis (NA)

There are a number of approaches to NA “but what they share is a focus in the ways in which we make sense of the world through stories (Green & Thorogood, 2010, p213)”. NA is seen as an approach that offers a way to see how individuals construct meaning in their lives by looking at what type of stories are told and the way in which they are told (Willig, 2009). Although I was interested in the stories young people told about their experiences with cancer, NA emphasises the importance of not focusing on particular narratives. Given that one of my research questions focused on what factors have influenced YP’s experiences, I did not feel NA was appropriate as the study no longer focused solely on narratives but factors that have influenced this. I was also aware that participants in this study had taken part in a NT intervention and felt that NA was too closely aligned to the intervention.

Interpretative Phenomenological Analysis (IPA)

Another method I considered was IPA, which focuses on the lived experiences of participants (Smith & Osborn, 2008). IPA aims to “explore in detail how participants are making sense of their personal and social world (Smith & Osborn, 2008, p53)”, whilst acknowledging the role of the researcher and the relationship between the researcher and the participant (Willig, 2009). As this study focused on a broader investigation of YP’s experiences with cancer and factors that had influenced this, rather than focusing on interpreting how the participants make sense of their experiences, I decided that IPA was not appropriate. Furthermore, IPA requires a homogenous group and given that

participants had different diagnoses and treatments it was decided that this method would not be appropriate.

Grounded Theory (GT)

GT is a method that aims to produce new theories that are grounded within empirical data (Green & Thorogood, 2010). Although it can be used for exploratory research questions, Willig (2009) argues that using GT for these is a descriptive exercise, rather than explanatory exercise, that produces new theories. She suggests, therefore, that GT should be reserved for the study of social psychological processes (Willig, 2009). It was therefore deemed inappropriate for this study.

Discourse Analysis (DA)

DA focuses on the role of language in the construction of reality. It highlights “what people do with language and it emphasizes the performance qualities of discourse” (Willig, 2009, p. 95). For example, it looks at the function and consequences of making reference to certain things (Willig, 2009), such as ‘coping’ or ‘low mood’.

However, it was deemed inappropriate for this study as it has been seen as a method most appropriate for naturally occurring text and conversation (Potter & Hepburn, 2005).

Appendix 3 – Information Sheet for Participants Aged Under 18

University College London Hospitals 
NHS Foundation Trust



Department of Child & Adolescent Psychological Services

Sixth Floor Central
250 Euston Road
London, NW1 2PG

School of Psychology
Stratford Campus
Water Lane
London
E15 4LZ

Young person information sheet (for those under 18)

Project Title: An exploration of the experiences of those affected by cancer and taking part in a narrative-based programme.

I would like to invite you to take part in a study exploring your experiences of cancer and beading, a project that you recently took part in at University College London Hospital (UCLH). The purpose of this letter is to tell about the study so you can decide if you want to take part.

Purpose of the study

Cancer has an impact on the lives of adolescents, as well as their families. However, there is a lack of research looking at the different support for young people and their families affected by cancer. A new intervention, called the Beading Project, was recently introduced on the Teenage Cancer Trust Ward at UCLH. This project aims to explore what it is like to have been affected by cancer and taking part in this project.

Why have I been invited?

Everyone who took part in this project, who agreed that they were happy to be contacted, is being invited to take part in this research.

Do I have to take part?

It is up to you to decide to join the study. I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign a form to say you are happy to take part.

What will happen to me if I take part?

You will be interviewed by the researcher for about an hour. Your parent/guardian will not be in the room during the interview. See the form at the end of this information sheet for an idea of some of the questions that may be asked.

Interviews can take place at one of three locations: UCLH in a private clinic room; UEL in a private room; or in your home. You are able to choose a location that suits you best.

Interviews will be audiotaped and written up by the researcher, Ben Weiner. Only the researcher will have access to the recorded interview.

Expenses and payments

Should you travel to UCLH or UEL, you can claim your travel expenses, providing you produce a receipt of your travel.

What are the possible disadvantages and risks of taking part?

There should be no disadvantages or risks to taking part. Should you find talking about your experiences difficult or find that it makes you feel sad, you will be offered the opportunity to break or stop the interview. You will also be offered the opportunity to speak to someone about this if you would like this.

What are the potential benefits of taking part?

Taking part in the study will help us to make sure we are making the Beading Project relevant to those taking part. Taking part in the study may also help you remember your experiences and some of things that were helpful to you.

What happens if I don't want to continue with the study?

You do not have to take part in this study and should not feel that you have to. You are free to withdraw at any time, without giving reason. If you want to stop taking part, you can without any consequences and without giving a reason. If you choose to withdraw during or after the interview you will be asked whether you would be happy for the information you have given to be used in the write up of this study – people will not be able to identify what you have said.

What happens when the research study stops?

Once you have finished your interview, the researcher (Ben Weiner) will write up the interview, using different names to ensure you cannot be identified. The recordings of these interviews will then be destroyed.

Will my taking part in the study be kept confidential?

Yes. This research will follow ethical and legal practice and all information about you will be handled in confidence.

Any information that gives away your identity will be removed or anonymised. Different names will be used when the research is written up to make sure you cannot be identified. After interviews have been written up, their recordings will be destroyed. Only members of the research team (i.e. the researcher and their supervisors) will have access to this information.

Any information given will be kept confidential unless anything is mentioned about harm to self or others. In the event of risk the participant will be informed of the action that is necessary to ensure safety of participants and others (e.g. contacting the relevant professional).

Questions and Complaints

If you have a questions or concerns about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (u1037651@uel.ac.uk; telephone number: XXX).

If you remain unhappy and wish to complain formally, you can do this by contacting the study's supervisor, Dr Kenneth Gannon (School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020822304576. Email address: k.n.gannon@uel.ac.uk), or the Chair of the School of Psychology Research Ethics Sub-committee, Dr. Mark Finn (School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020 8223 4493. Email: m.finn@uel.ac.uk).

What will happen to the results of the research study?

The results of the study will be written up as part of my Doctorate in Clinical Psychology at the University of East London (UEL). The study will also hopefully be published in an academic journal. You can request a summary of the research once it has been written up, if you are interested in hearing the outcome of the research.

Thank you for taking the time to read this. If you are interested in taking part in the project, please contact the researcher using the contact details below.

Kind Regards,

Ben Weiner

Trainee Clinical Psychologist

u1037651@uel.ac.uk

Telephone number: XXX

Appendix 4 – Information Sheet for Parent/Guardian of Participants Aged Under 18

University College London Hospitals 
NHS Foundation Trust



Department of Child & Adolescent Psychological Services

Sixth Floor Central
250 Euston Road
London, NW1 2PG

School of Psychology
Stratford Campus
Water Lane
London
E15 4LZ

Parent/guardian information sheet

Project Title: An exploration of the experiences of those affected by cancer and taking part in a narrative-based programme.

I would like to invite your son/daughter to take part in a study exploring their experiences of cancer and beading, a project that they recently participated in at University College London Hospital (UCLH). The purpose of this letter is to provide you with the information that you need to consider in deciding whether you are happy for your son/daughter to participate in this research study. I have also enclosed a copy of an information sheet for your son/daughter for you to give to them.

Purpose of the study

Cancer has a significant impact on the lives of adolescents, as well as their families. However, there is limited research exploring the different interventions

to support young people and their families affected by cancer. A new intervention, called the Beading Project, was recently introduced on the Teenage Cancer Trust Ward at UCLH. This project aims to explore what it is like to have been affected by cancer and taking part in this project.

Why has my son/daughter been invited?

Everyone who took part in this project, who agreed that they were happy to be contacted, is being invited to take part in this research.

Do they have to take part?

It is up to you and your son/daughter to decide to join the study. I will describe the study and go through this information sheet. If you agree for them to take part, I will then ask you to sign a consent form to say you are happy for them to participate and will ask your son/daughter to sign an assent form.

What will happen to my son/daughter if they take part?

Your son/daughter will be interviewed for approximately an hour – see the attached interview schedule for an outline of some of the questions that may be asked. The interview will be conducted with the researcher and your son/daughter; you will be asked to wait outside.

Interviews can take place at one of three locations: UCLH in a private clinic room; UEL in a private room; or in your home. You and your son/daughter are able to choose a location that suits you best.

Interviews will be audiotaped and transcribed by the researcher, Ben Weiner. Only the researcher will have access to the recorded interview.

Expenses and payments

Should you and your son/daughter travel to UCLH or UEL, you can claim your travel expenses, providing you produce a receipt of your travel.

What are the possible disadvantages and risks of taking part?

There are no potential adverse effects anticipated as a consequence of taking part in this study. Should participants find talking about their experiences difficult or find that it makes them feel sad, they will be offered the opportunity to break or terminate the interview. Participants may also be offered sources of help and support, should this be appropriate. For example the Teenage Cancer Trust provides an independent voice of support.

What are the potential benefits of taking part?

Participation in the study will contribute towards ensuring that the Beading Project is tailored to meet the needs of those taking part. Additionally, your son/daughter may feel empowered by discussing their experiences as it may help them reflect on them.

What happens if my son/daughter does not want to continue with the study?

Your son/daughter is not obliged to take part in this study and should not feel coerced. They are free to withdraw at any time, without giving reason. Should they choose to withdraw from the study they may do so without disadvantage and without any obligation to give a reason. Should they withdraw during or after the interview I will ask both you and your son/daughter whether you would be happy for their data to be used in the write up of this study – their data will of course be anonymised.

What happens when the research study stops?

Once interviews have been conducted, the researcher (Ben Weiner) will transcribe the interviews, using pseudonyms to ensure confidentiality. The recordings of these interviews will then be destroyed. Data will then be analysed and written up for academic submission.

Will my son/daughter's taking part in the study be kept confidential?

Yes. This research will follow ethical and legal practice and all information about you will be handled in confidence.

Any identifying information will be removed or anonymised from the transcriptions and pseudonyms will be used in each transcript so that anonymity is preserved. Personal details obtained in the consent form will be kept separate from the data and all records will be kept in locked filing cabinets. Computer records will be password-protected and stored on computers that require a password and log-in details. After interviews have been transcribed, their recordings will be destroyed. After examination of the research any information relating to the identity of participants will be destroyed. Only members of the research team (i.e. the researcher and their supervisors) will have access to the anonymised transcripts.

Transcripts will be kept securely for a period of five years after the study is complete. After this date all data and consent forms will be destroyed, in accordance with the Data Protection Act (1998).

All information provided by participants will be kept confidential unless the participant discloses information regarding risk to themselves or others (e.g. intent to harm others or themselves). In the event of risk the participant will be informed of the action that is necessary to ensure safety of participants and others (e.g. contacting the relevant professional).

Questions and Complaints

If you have a questions or concerns about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (u1037651@uel.ac.uk; telephone number: XXX).

If you remain unhappy and wish to complain formally, you can do this by contacting the study's supervisor, Dr Kenneth Gannon (School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020822304576. Email address: k.n.gannon@uel.ac.uk), or the Chair of the School of Psychology Research Ethics Sub-committee, Dr. Mark Finn (School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020 8223 4493. Email: m.finn@uel.ac.uk).

What will happen to the results of the research study?

The results of the study will be written up for academic submission as part of my Doctorate in Clinical Psychology at the University of East London (UEL). The study will also hopefully be published in an academic journal. Participants can request a summary of the research once it has been written up, should they be interested in hearing the outcome of the research.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South East London Research Ethics Committee. It has also been reviewed and given a favourable opinion by the UEL Ethics Committee.

Thank you for taking the time to read this. If your son/daughter is interested in taking part in the project, please contact the researcher using the contact details below.

Kind Regards,

Ben Weiner

Trainee Clinical Psychologist

u1037651@uel.ac.uk

Telephone number: XXX

Appendix 5– Information Sheet for Participants Aged 18 and Above

University College London Hospitals 
NHS Foundation Trust



Department of Child & Adolescent Psychological Services

Sixth Floor Central
250 Euston Road
London, NW1 2PG

School of Psychology
Stratford Campus
Water Lane
London
E15 4LZ

Young person's information sheet (for those 18+)

Project Title: An exploration of the experiences of those affected by cancer and taking part in a narrative-based programme.

I would like to invite you to take part in a study exploring your experiences of cancer and beading, a project that you recently participated in at University College London Hospital (UCLH). The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this research study.

Purpose of the study

Cancer has a significant impact on the lives of adolescents, as well as their families. However, there is limited research exploring the different interventions to support young people and their families affected by cancer. A new intervention, called the Beading Project, was recently introduced on the Teenage Cancer Trust Ward at UCLH. This project aims to explore what it is like to have been affected by cancer and taking part in this project.

Why have I been invited?

Everyone who took part in this project, who agreed that they were happy to be contacted, is being invited to take part in this research.

Do I have to take part?

It is up to you to decide to join the study. I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign a consent form.

What will happen to me if I take part?

Participants will be interviewed for approximately an hour – see the attached interview schedule for an outline of some of the questions that may be asked

Interviews can take place at one of three locations: UCLH in a private clinic room; UEL in a private room; or in your home. You are able to choose a location that suits you best.

Interviews will be audiotaped and transcribed by the researcher, Ben Weiner. Only the researcher will have access to the recorded interview.

Expenses and payments

Should you travel to UCLH or UEL, you can claim your travel expenses, providing you produce a receipt of your travel.

What are the possible disadvantages and risks of taking part?

There are no potential adverse effects anticipated as a consequence of taking part in this study. Should you find talking about your experiences difficult or find that it makes you feel sad, you will be offered the opportunity to break or terminate the interview. Participants may also be offered sources of help and support, should this be appropriate. For example the Teenage Cancer Trust provides an independent voice of support.

What are the potential benefits of taking part?

Participation in the study will contribute towards ensuring that the Beading Project is tailored to meet the needs of those taking part. Additionally, participants may feel empowered by discussing their experiences as it may help them reflect on them.

What happens if I don't want to continue with the study?

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time, without giving reason. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason. Should you withdraw during or after the interview you will be asked whether you would be happy for your data to be used in the write up of this study – your data will of course be anonymised.

What happens when the research study stops?

Once interviews have been conducted, the researcher (Ben Weiner) will transcribe the interviews, using pseudonyms to ensure confidentiality. The recordings of these interviews will then be destroyed. Data will then be analysed and written up for academic submission.

Will my taking part in the study be kept confidential?

Yes. This research will follow ethical and legal practice and all information about you will be handled in confidence.

Any identifying information will be removed or anonymised from the transcriptions and pseudonyms will be used in each transcript so that anonymity is preserved. Personal details obtained in the consent form will be kept separate from the data and all records will be kept in locked filing cabinets. Computer records will be password-protected and stored on computers that require a password and log-in details. After interviews have been transcribed, their recordings will be destroyed. After examination of the research any information relating to the identity of participants will be destroyed. Only members of the research team (i.e. the researcher and their supervisors) will have access to the anonymised transcripts.

Transcripts will be kept securely for a period of five years after the study is complete. After this date all data and consent forms will be destroyed, in accordance with the Data Protection Act (1998).

All information provided by participants will be kept confidential unless the participant discloses information regarding risk to themselves or others (e.g. intent to harm others or themselves). In the event of risk the participant will be informed of the action that is necessary to ensure safety of participants and others (e.g. contacting the relevant professional).

Questions and Complaints

If you have a questions or concerns about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (u1037651@uel.ac.uk; telephone number: XXX).

If you remain unhappy and wish to complain formally, you can do this by contacting the study's supervisor, Dr Kenneth Gannon (School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020822304576. Email address: k.n.gannon@uel.ac.uk), or the Chair of the School of Psychology Research Ethics Sub-committee, Dr. Mark Finn (School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020 8223 4493. Email: m.finn@uel.ac.uk).

What will happen to the results of the research study?

The results of the study will be written up for academic submission as part of my Doctorate in Clinical Psychology at the University of East London (UEL). The study will also hopefully be published in an academic journal. Participants can request a summary of the research once it has been written up, should they be interested in hearing the outcome of the research.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South East London Research Ethics Committee. It has also been reviewed and given a favourable opinion by the UEL Ethics Committee.

Thank you for taking the time to read this. If you are interested in taking part in the project, please contact the researcher using the contact details below.

Kind Regards,

Ben Weiner

Trainee Clinical Psychologist

u1037651@uel.ac.uk

Telephone number: XXX

Appendix 6 – Assent Form for Participants Aged Under 18

University College London Hospitals 

NHS Foundation Trust

**Department of Child & Adolescent Psychological
Services**

Sixth Floor Central
250 Euston Road
London, NW1 2PG



School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

Assent to participate in a research study for those under 18

Project Title: An exploration of the experiences of those affected by cancer and taking part in a narrative-based programme.

Please tick box

1. I confirm that I have read and understood the young person's information sheet and I have understood what it says. ☐
2. I have thought about the information given about the study, and asked my parents or the researcher about any questions I have. ☐
3. I understand that I do not have to take part in the study. I know I can leave the study at any time, and that I do not need to give a reason why. I understand that this will not change the care I get from the doctors and nurses at the hospital, and that no one will be angry if I change my mind. ☐
4. I would like to take part in the study, but I know I can always change my mind later if I want to. ☐

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Name of Young Person treated at UCLH (BLOCK CAPITALS) – only if different to
above

.....

Young Person treated at UCLH's Signature – only if different to above

.....

Date:

Appendix 7 – Consent Form for Parent/Guardian of Participant Aged Under 18

University College London Hospitals 

NHS Foundation Trust



Department of Child & Adolescent Psychological Services

Sixth Floor Central

250 Euston Road

London, NW1 2PG

School of Psychology

Stratford Campus

Water Lane

London

E15 4LZ

Parent/Guardian Consent for their son/daughter to participate

Project Title: An exploration of the experiences of those affected by cancer and taking part in a narrative-based programme.

Please tick box

aa

1. I have read the information sheet relating to the above research study and both me and my son/daughter have been given a copy to keep. ☐
2. The nature and purposes of the research have been explained to both of us, and we have had the opportunity to discuss the details and ask questions about this information. ☐
3. I understand what is being proposed and the procedures in which my son/daughter will be involved have been explained to me. ☐

4. I understand that my son/daughter's involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed. ☐
5. I hereby freely and fully consent for my son/daughter to participate in the study which has been fully explained to me. ☐
6. Having given this consent I understand that my son/daughter has the right to withdraw from the study at any time without disadvantage and without being obliged to give any reason. ☐
7. I also understand that should my son/daughter withdraw during or after the interview the researcher will ask me whether my son/daughter and I am are happy for their data to be used anonymously in the write up of the study. ☐

Parent/Guardian Name (BLOCK CAPITALS)

.....

Parent/Guardian Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Child's Name

.....

Date:

Appendix 8 – Consent Form for Participants Aged 18 and Above



University College London Hospitals **NHS**
NHS Foundation Trust

Department of Child & Adolescent Psychological Services

Sixth Floor Central
250 Euston Road
London, NW1 2PG

School of Psychology
Stratford Campus
Water Lane
London
E15 4LZ

Consent to participate in a research study for those 18+

Project Title: An exploration of the experiences of those affected by cancer and taking part in a narrative-based programme.

Please tick box

1. I have read the information sheet relating to the above research study and have been given a copy to keep. ☐
2. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. ☐
3. I understand what is being proposed and the procedures in which I will be involved have been explained to me. ☐

4. I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed. ☐
5. I hereby freely and fully consent to participate in the study which has been fully explained to me. ☐
6. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. ☐
7. I also understand that should I withdraw during or after the interview the researcher will ask me whether I am happy for my data to be used anonymously in the write up of the study. ☐

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Name of Young Person treated at UCLH (BLOCK CAPITALS) – only if different to above

.....

Young Person treated at UCLH's Signature – only if different to above

.....

Date:

Appendix 9 – Cover Questionnaire

Date of interview	
Participant number	
Date of birth	
Age at interview	
Gender	
Ethnicity	
Diagnosis	
Age at diagnosis	
Time since diagnosis	
Time since most recent treatment	
Type of treatment	

Appendix 10 – Interview Schedule

1. What was / is it like living with cancer
 - How would you describe your experience of living with cancer
 - What happened during this time
 - Who was around
 - What was hard
 - What was helpful
2. Does / how does living with cancer impact upon your life and the life of those around you
 - What happens day-to-day when you live with cancer
 - What kind of conversations take place
 - What do you do every day
 - Are there some things you no longer do / forget about
 - What is this like
3. What has helped you cope with the more difficult parts of your journey with cancer
 - Clinical interventions – medical, psychological, social
 - Family, friends
 - Activities
 - Remembering hopes and dreams
 - Individual coping strategies
4. Has the way you think about living with cancer been influenced by any of the things that helped you cope
 - If so, how come
 - If not, why do you think
 - Beading?
 - did it helped them to remember certain stories/parts of their lives that they had forgotten?

5. Do you talk about your experience of living with cancer differently

- How come
- In what way
- What did you think influences this
- Why do you think this is

Appendix 11 – University of East London Ethical Approval

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

A handwritten signature in blue ink, which appears to read 'Mark Finn', is written over a light blue horizontal line.

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



Appendix 12 – NHS Research Ethics Committee Approval



Health Research Authority

NRES Committee London - South East

Room 4W/12

4th Floor West

Charing Cross Hospital

Fulham Palace Road

London

W6 8RF

Telephone: 020 3311 7254

Facsimile: 020 3311 7280

12 July 2012

Mr Ben Weiner
Flat 65, Garand Court
Eden Grove
London
N7 8EW

Dear Mr Weiner

Study title: **An exploration of the experiences of people affected by cancer and taking part in a narrative-based programme.**

REC reference: **12/LO/0904**

Thank you for your letter of 10 July 2012, responding to the Committee's request for further information on the above research and submitting revised documentation

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		17 May 2012
Evidence of insurance or indemnity		05 April 2012
Investigator CV		
Other: Supervisor CV		
Other: Referee's report: University of East London requesting amendments to Registration Document		26 January 2012
Other: Referee's report: Responding letter		11 February 2012
Other: Referee's report: Approval of Registration Document		16 February 2012
Other: Interview schedule: Parent/sibling	1	05 April 2012
Other: Interview schedule: Young person	1	05 April 2012
Participant Consent Form: 18+ consent form	2	10 July 2012
Participant Consent Form: Young person (under 18) assent form	2	10 July 2012

Participant Consent Form: Parent-Guardian consent form	2	10 July 2012
Participant Information Sheet: 18+ information sheet	2	10 July 2012
Participant Information Sheet: Young person information sheet	2	10 July 2012
Participant Information Sheet: Parent-Guardian information sheet	2	10 July 2012
Protocol	2	10 July 2012
REC application		24 May 2012
Response to Request for Further Information		10 July 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website >
After Review

12/LO/0904

**Please quote this number on all
correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



pp

Professor David Caplin

Chair

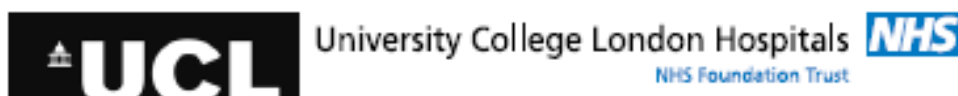
Email: janhoi.mcgregor@imperial.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Kenneth Gannon, The University of East London

Ms Emma Clark, University College London Hospitals NHS
Foundation Trust

Appendix 13 – Approval from the Joint Research and Development Office for UCL/UCLH/Royal Free



Joint Research Office

Office Location:
1st Floor Maple House
149 Tottenham Court Road
London W1T 7DN

Postal Address:
UCL,
Gower Street
London WC1E 6BT

Tel: 020 3447 7483 Fax: 020 3447 9937

Websites: www.uclh.nhs.uk www.ucl.ac.uk www.ucl.ac.uk/jro

FINAL R&D APPROVAL – NHS PERMISSION

20/07/2012

Mr Ben Weiner
Flat 65
Garand Court
Eden Grove
London
N7 8EW
UK

Dear Mr Ben Weiner

Project ID: 12/0308 (Please quote in all correspondence)
REC Ref: 12/LO/0904
Title: An exploration of the experiences of people affected by cancer and taking part in a narrative-based programme.

Thank you for registering the above study with the Joint Research Office (UCLH site). I am pleased to inform you that your study now has local R&D approval (NHS permission) to proceed and recruit participants at University College London Hospitals NHS Foundation Trust subject to sponsor confirmation.

Please note that all documents received have been reviewed and this approval is granted on the basis of the key documents provided which are ethically approved by the Research Ethics Committee:

Document	Date
REC approval and REC approved documents	12/07/2012

As Principal Investigator you are required to ensure that your study is conducted in accordance with the requirements on the attached sheet. These include the conditions of your NHS permission.

Do not hesitate to contact a member of the team should you have any queries.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Suzanne Blinks'.

Professor Monty Mythen
Director of Research and Development
UCL/UCLH/Royal Free Joint Research Office

pp Suzanne Blinks



UCL Hospitals is an NHS Foundation Trust comprising: The Eastman Dental Hospital, The Heart Hospital, Hospital for Tropical Diseases, National Hospital for Neurology and Neurosurgery, The Royal London Hospital for Integrated Medicine and University College Hospital (incorporating the former Middlesex and Elizabeth Garrett Anderson Hospitals).

Version 21 June 2012

Responsibilities of the Researcher

Conditions of NHS permission

Your research has been granted NHS permission by the Joint Research Office on behalf of University College London Hospitals NHS Foundation Trust.

As a condition of the NHS permission you must comply with:

- Applicable Joint Research Office's Standard Operating Procedures
- Department of Health's Research Governance Framework for Health and Social Care
- Research Ethics Committee notice of favourable opinion
- Data Protection Act, Caldicott Principles and Trust Information Governance Policy.
- All other relevant legislation and regulatory approvals including the following if applicable
 - Medicines and Healthcare products Regulatory Agency
 - notice of acceptance of a clinical trial of investigational medicinal product (CTIMP)
 - notice of no objection of a clinical investigation for a medical device
 - Human Tissue Act 2004 and the Codes of Practice with special relevance to Code 9 Research
 - Human Tissue (Quality and Safety for Human Application) Regulations 2007

Responsibilities for Research Teams

As Principal Investigator you are required to ensure that:

- The roles and responsibilities of all members of the research team are documented in a delegation log and that all team members are made aware of these.
- All researchers conducting the study have up-to-date appropriate employment contracts or honorary contracts where needed.
- All researchers are suitably trained, qualified and experienced to carry out duties delegated to them and if conducting a clinical trial, have up-to-date Good Clinical Practice (GCP) training (updated every 2 years).

Responsibilities for the Principal Investigator in relation to tissue and data in the absence of a study agreement:

- After ethics approval for the study has expired, you shall ensure that tissues are disposed of in accordance with the protocol and Human Tissue Act 2004, transferred to a licensed tissue bank or used under a new ethically approved research project.
- Ensure that all necessary arrangements are in place for appropriate transfer, storage, handling, retention (archiving) and, if applicable, destruction of study data. The sponsor will act as the custodian of such data.

Reporting on Recruitment

Please ensure that you notify the Joint Research Office with:

- Confirmation of recruiting your first patient by emailing RandD@uclh.nhs.uk.
- There is also a requirement to report accrual on a regular basis. If your study has been adopted onto the NIHR portfolio you will be contacted directly by the NIHR Clinical Research Network Coordinating Centre. For all other studies you are required to provide an update to the Joint Research Office on recruitment every 6 months.



UCL Hospitals is an NHS Foundation Trust comprising: The Eastman Dental Hospital, The Heart Hospital, Hospital for Tropical Diseases, National Hospital for Neurology and Neurosurgery, The Royal London Hospital for Integrated Medicine and University College Hospital (incorporating the former Middlessex and Elizabeth Garrett Anderson Hospitals).

Version 21 June 2012

Reporting Study Events

Unexpected events and incidents

Please ensure that your study team reports the following to the sponsor as required by the protocol or sponsor SOPs:

- For CTIMPs
 - All suspected unexpected serious adverse events (SUSARs),
 - Protocol violations, serious breaches of protocol and of GCP
 - Urgent safety measures
- For all other studies
 - All unexpected serious adverse events (SAE) related to the research protocol

Please ensure that your study team reports the following to the Joint Research Office:

- For all research
 - All complaints from NHS patients from UCLH should be reported in the first instance to the UCLH NHS Complaints Manager.
 - All research related incidents occurring at the UCLH should be reported through DATIX, the Trust Incident Reporting System (available on InSight).
- For CTIMPs
 - Please report all SUSARs and Serious Breaches of Protocol and GCP occurring at UCLH through DATIX.
- For all other studies
 - Please report unexpected SAEs related to the research protocol, serious breaches of protocol and GCP if applicable through DATIX.

Study progress and changes

Please ensure that your study team reports the following to the Joint Research Office:

- Amendments (including a request to extend the study)
- Monitoring activity information:
 - for non-commercially sponsored clinical trials provide a summary of corrective and preventive actions from monitoring reports, as agreed with the sponsor
 - for industry sponsored clinical trials provide a copy of the monitoring log on an annual basis, as agreed with the sponsor
 - annual progress reports submitted to REC (for UCL and UCLH sponsored research)
- Audit activity information:
 - Notification of audits or inspections
 - Audit reports (where possible, and in agreement with the sponsor, to provide a copy of the corrective and preventive actions arising from an audit)
- Notification of end of study or suspension of study
- Publications

Study documentation

Research teams are required to:

- Prepare and maintain a site file to ensure that data and documentation associated with the study are available for audit. Please refer to the SOP for Preparation of Site File JRO/RM&G/SOP-13 available at: <http://www.ucl.ac.uk/jro/standingoperatingprocedures>
- Contact the Archivist & Records Manager by email as soon as the study has been suspended or ended in order to arrange for archiving.

If you require any further information on the above please see the Joint Research Office website <http://www.ucl.ac.uk/jro>.

Joint Research Office Standard Operating Procedures are available at: <http://www.ucl.ac.uk/jro/standingoperatingprocedures>.



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Version 21 June 2012

Appendix 14– Change in Thesis Title Approval



Ben Weiner
65 Garand Court
Eden Grove
London N7 8EW

19 December 2012

Student number: 1037651

Dear Ben

Notification of a Change of Thesis Title:

I am pleased to inform you that the School Research Degree Sub-Committee has approved the change of thesis title. Both the old and new thesis titles are set out below:

Old thesis title: An exploration of the experiences of people affected by cancer and taking part in a narrative-based programme.

New thesis title: Young people's journeys with cancer and factors that influence their experiences.

Your registration period remains unchanged. Please contact me if you have any further queries with regards to this matter.

Yours sincerely,

A handwritten signature in black ink that reads "James J Walsh." The signature is written in a cursive style with a period at the end.

Dr James J Walsh
School Research Degrees Leader
Direct line: 020 8223 4471
Email: j.j.walsh@uel.ac.uk

cc. Ken Gannon

Appendix 15 – Transcription Conventions

()	Indicates pause in speech
[unclear]	Indicates that the person transcribing was not sure about what was said
=	Indicates where someone has finished another's sentence
[]	Indicates when the author wants to add comment e.g. [Ben laughs] or [someone enters room]
[interruption]	Brief interruptions shown by inserting interruption in square brackets e.g. Ben: And where did you find that information? Did you [Jay: On the internet], did you look specifically for something or you just looked it up?
(insert word)	when the transcribe was uncertain what was said but able to make a reasonable guess
,	Person speaking changes their sentence e.g Jay: Um I, because he lives in, he lives from far from us
-	Unfinished word e.g. Ben: Mm. How com-, how did you cope with that?

Adapted from Parker (2005)

Appendix 16 – Worked Extract Example

There are people around her with whom she can talk	674 When we would talk about it, it would be like, they 675 would kind of like tiptoe around the subject but I 676 wouldn't feel um I would be scared to be like open 677 about stuff.	Being different to those around her – she's happy to discuss it
	678 Ben: What do you mean by that? What do you mean 679 by open about stuff?	
Cancer and its treatments and how they can make you feel	680 Grace: Um I don't know. Some people find it really 681 difficult to talk about how even like the process of 682 what they'll be doing, like the chemotherapy and 683 being ill and <u>yeh</u> , how it's affected them a bit and 684 stuff like that. But I think I'm ok with that.	Comparison to others - seeing self as doing better than others
	685 Ben: And so would there be times where you'd be 686 able to talk about how difficult it was and if they 687 tiptoed around it or would you wait for them to bring it 688 up?	
Talking about others around her and the impact cancer has on them	689 Grace: I think I'd wait for the person to bring it up 690 because () for example my teachers, they're a bit 691 um () I think, I think a lot of people they just take it 692 harder than me. I don't know (1s) and that's, <u>yeh</u> 693 unless they ask you know <u>cos</u> I wouldn't want to 694 make them feel awkward or emotional or anything 695 like that.	Comparison to others – reacting differently Concern for others – perhaps wanting to protect others
	696 Ben: And have you noticed at all and I'm not saying 697 that necessarily have, have you noticed at all, any 698 changes in how you've thought of things over your 699 experiences? Have your perceptions changed at all?	
Something good has come out of cancer – feeling stronger	700 Grace: Not really, not really. I think I am the same as 701 I was before but a bit, () a bit stronger than that.	Reference to life before cancer
	702 Ben: Mm. And why do you think that is? Why do you 703 think it is that you feel a bit stronger?	
Sense of having to get on with things and look forward rather than being stuck in the moment	704 Grace: I think because it's the second time as well so 705 () I've kind of forced myself to like move on with it, 706 get on with things () and I don't really, if I'm sad 707 about something, I'll be sad for about ten minutes 708 and then I'll move on because it's not like, there's no 709 point () mm.	Second time with cancer – learning from experience It can make you feel sad Conscious effort to move forward and do something

Appendix 17 – Code Book

Number	Initial Code	Extract (line number)
1.	Come to terms with it	
2.	Doesn't bother me	
3.	Finding solutions	
4.	Focus on future	
5.	Focus on getting better	
6.	Get on with it	
7.	Get used to it	
8.	Not a big deal	
9.	Remembering experience	
10.	Self-talk	
11.	Time – harder at beginning	
12.	Time – easier with time	
13.	Age	
14.	Being a teenager	
15.	Cancer is indiscriminate	
16.	Inexplicable	
17.	Individual differences in cancer experience	
18.	Faith	
19.	Family context	
20.	Life before cancer	
21.	Personal attributes	
22.	What others think	
23.	Being asked questions	
24.	Being different - image	
25.	Being different – being ill	
26.	Being different – treated differently	
27.	Dependency – being dependent	

28.	Dependency – ambivalence over whether it is a good or a bad thing	
29.	Education – wanting to go back	
30.	Education - impact	
31.	Hospital – not wanting to be there	
32.	Hospital – multiple trips	
33.	Impact on relationships	
34.	Lifestyle changes	
35.	Routine	
36.	Stuck at hospital	
37.	Stuck at home	
38.	Wanting independency	
39.	Wanting to return to normality	
40.	Chemotherapy	
41.	Having tests	
42.	Injections	
43.	Medication	
44.	Pic line / cannula	
45.	Steroids	
46.	Treatment time	
47.	Waiting time	
48.	Changed perspective	
49.	Inspiring and helping others	
50.	Mixed experience of cancer	
51.	New opportunities	
52.	Positive impact	
53.	Can't do things	
54.	Can't do things – school / uni / work	
55.	Can't do things – sport	
56.	Lack of privacy	
57.	Missing out	
58.	Not doing anything	

59.	Not going outside	
60.	Physical impact – eating	
61.	Physical impact – energy	
62.	Physical impact – feeling ill	
63.	Physical impact – getting ill	
64.	Physical impact – hair loss	
65.	Physical impact – mobility	
66.	Physical impact – nausea and vomiting	
67.	Physical impact - pain	
68.	Physical impact – peeling & soreness	
69.	Physical impact - senses	
70.	Physical impact - sleep	
71.	Physical impact - swelling	
72.	Physical impact – things you can see	
73.	Physical impact - weakness	
74.	Physical impact – weight	
75.	Shaving hair	
76.	Side effects	
77.	Symptoms	
78.	Wig	
79.	Bad experience of hospital	
80.	Bad experience with staff	
81.	Boredom	
82.	Diagnosis – hearing the news	
83.	Emotional impact - anger	
84.	Emotional impact – annoyed	
85.	Emotional impact - ashamed	
86.	Emotional impact - crying	
87.	Emotional impact – feeling down	
88.	Emotional impact - many	
89.	Emotional impact – nervous	
90.	Emotional impact – scared	

91.	Emotional impact – shocked	
92.	Experience of treatment	
93.	Frustration	
94.	Having cancer is a difficult experience	
95.	Hopelessness	
96.	Isolating	
97.	Not a nice patient	
98.	Not wanting to talk	
99.	Not wanting treatment	
100.	Not wanting visitors	
101.	Overthinking	
102.	Reminders that you're ill	
103.	Stress	
104.	Unfair	
105.	Vulnerable	
106.	Wanting to be alone	
107.	Being brought things	
108.	Being inspired & learning from others with cancer	
109.	Being inspired & learning from others without cancer	
110.	Being listened to	
111.	Being told information	
112.	Encouragement	
113.	Family joining in	
114.	Feeling safe	
115.	Good experience with staff	
116.	Not wanting to be alone	
117.	Others - concerned about me	
118.	Others - talking to me	
119.	Shared experience	
120.	Support – accessing it	
121.	Support – appreciating it	
122.	Support – family	

123.	Support – Friends	
124.	Support - others	
125.	Support - partner	
126.	Support – staff	
127.	Visits	
128.	Concern for others	
129.	Impact on family	
130.	Impact on others	
131.	Impact on partner	
132.	Activities – available	
133.	Activities – enjoyable	
134.	Being strong	
135.	Control	
136.	Determination – willpower	
137.	Distraction	
138.	Doing normal things	
139.	Entertainment	
140.	Forgetting you're ill	
141.	Going out	
142.	Humour	
143.	Interacting with other patients	
144.	Keeping calm	
145.	Taking the lead	
146.	Talking – being open	
147.	Talking - it's good to talk	
148.	Being positive	
149.	Comparison to others	
150.	Feeling lucky	
151.	Gratefulness	
152.	Looking forward to something	
153.	Relief	
154.	Disbelief – it won't happen to me	

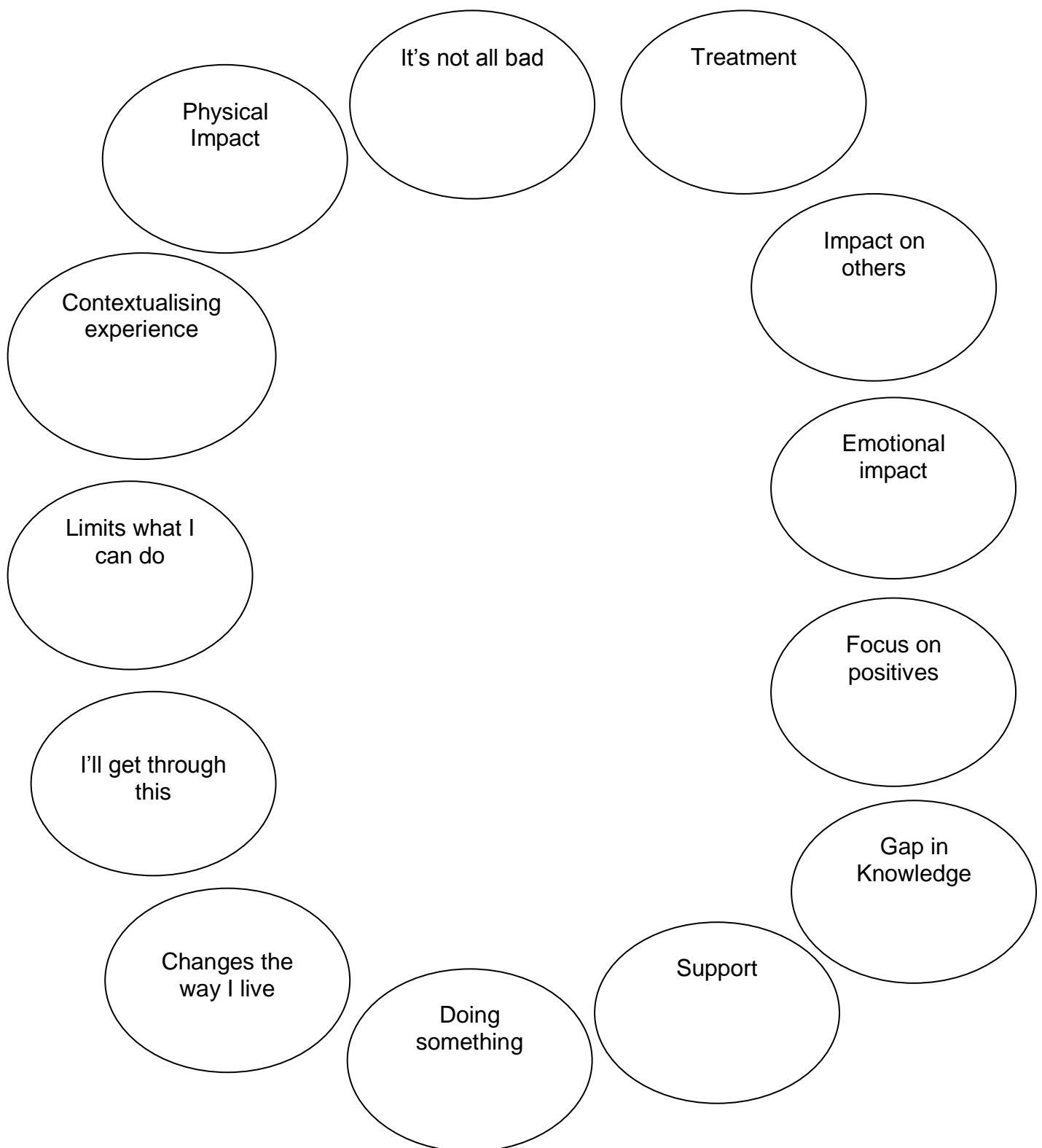
155.	Uncertainty - Death & Dying	
156.	Uncertainty –future	
157.	Uncertainty - diagnosis	
158.	Uncertainty – not knowing	
159.	Wanting to know the facts	
160.	Interview process- rhetoric questions	
161.	Interview process - Can't quite say something	
162.	Interview process - talking about others	
163.	Interview process - Giving example	
164.	Interview process - shift towards positive	

Appendix 18 – Coded Extract Example

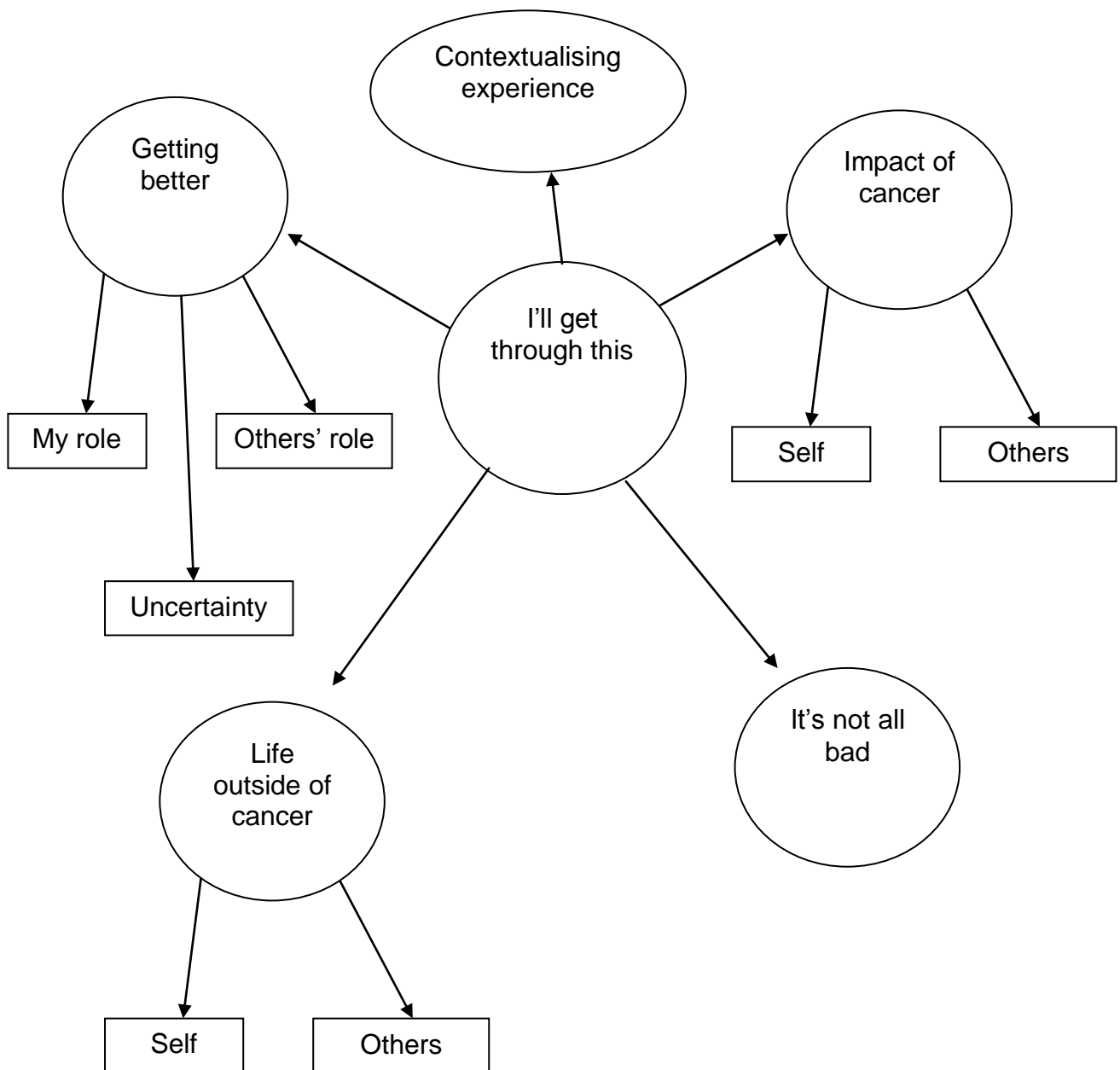
Number	Initial code	Extract (line number)
26.	Being different - treated differently	<p>Ben: So it's impacted on everybody's life [Eleni: mm].</p> <p>And how did you know that it was impacting on your family's life?</p> <p>Eleni: my brothers they, ok first of all they like, they kept coming up to me, they, they showed me more like affection than they did before they knew something was wrong but um they weren't sure what it was (2102-2109)</p>
		<p>Ben: And you said earlier that they'd talk to you about normal things and, and kind of help you pass the time. Um and I also heard how your family would make you food when you were at home. I'm wondering if there were other things about your friends and family that were helpful.</p> <p>Jay: Um () I think I () not really but, I think the bad thing about that was, the only bad thing that I felt about that was they were treating me di-, a bit different. Cos if they know that I was kind of weaker so they let me do what I want as well. Like mostly, mostly um I would actually watch tv but then they would interrupt and I, and I would usually let them watch but they actually let me watch for a change. I felt a bit, I actually felt quite good and bad because, good because I'm, I could keep watching what I was watching and bad about um I wasn't actually being treated normally.</p> <p>Ben: Mm. What was that like? I mean it sounds like it was good and bad. Um the positives that you got to watch whatever you wanted to watch but I'm</p>

		<p>interested in this idea of being treated differently [Jay: mm]. Can you tell me more about that?</p> <p>Jay: Like usually um throughout it, they would usually nag me about doing studying and everything. Now they just let me chill out mostly, yeh, which I felt was I felt was kind of good and bad cos yeh I didn't really like study that much so I could just do whatever I wanted [Ben: mm] and bad because usually it's not right, like, I felt that it wasn't normal for me to actually do that [Ben: mm], yeh. (7443-7472)</p>
		<p>Ben: You said you spent a lot more time at home but I am wondering what else was different.</p> <p>Hasan: Um how people were acting to me. Like before they'd be just like normal and now everyone's like 'are you ok?', like they're super concerned, like seeing if I'm ok (3093-3099)</p>
		<p>Ben: And you said that people in the lift would talk to you or people would look at you [P7: yeh] and this might sound like a strange question but I don't want to make an assumption that I [P7: yeh], is that a good thing or a bad thing that people would talk to you?</p> <p>You said it was strange. I just wasn't sure.</p> <p>Karen: Um I think it depends on what sort of person you are. I just looked at it like they's, they was pitying or 'poor little cancer girl'. So I didn't really like it. I'd still be polite back and everything but I didn't like it because I knew that they wouldn't talk to me if I looked like how I used to look (3932-3943)</p>

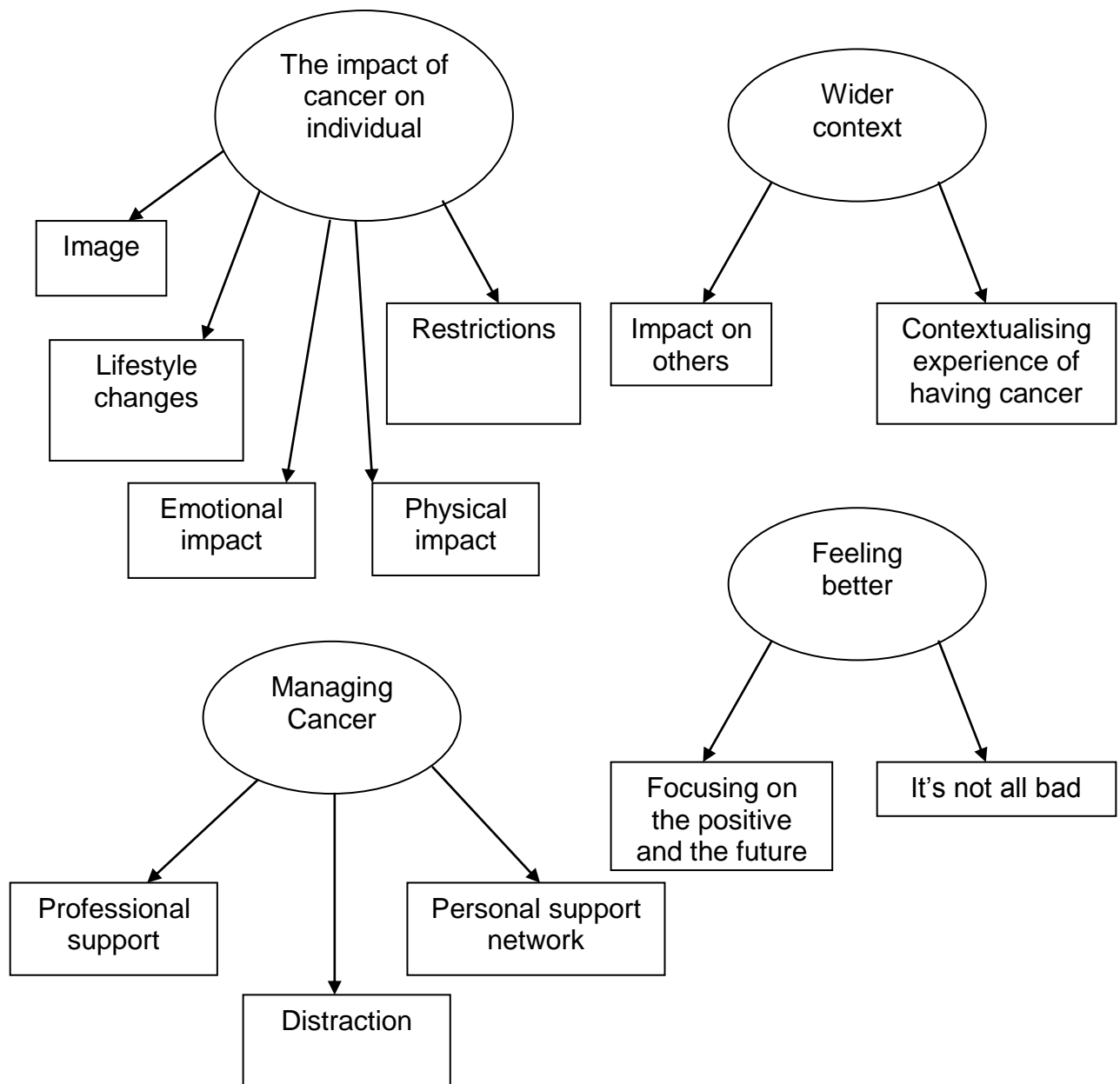
Appendix 19 – Provisional themes



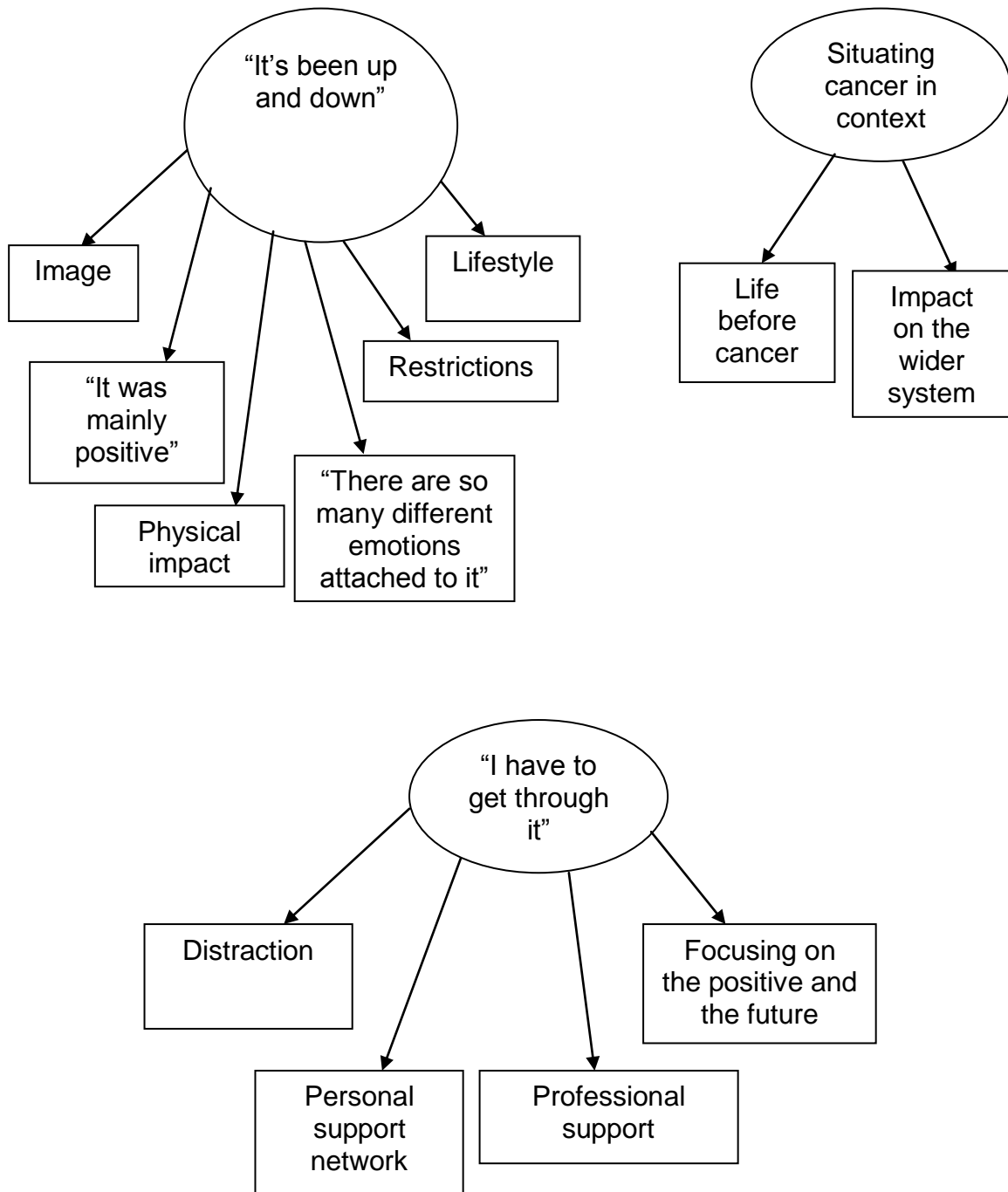
Appendix 20 – Thematic Map One



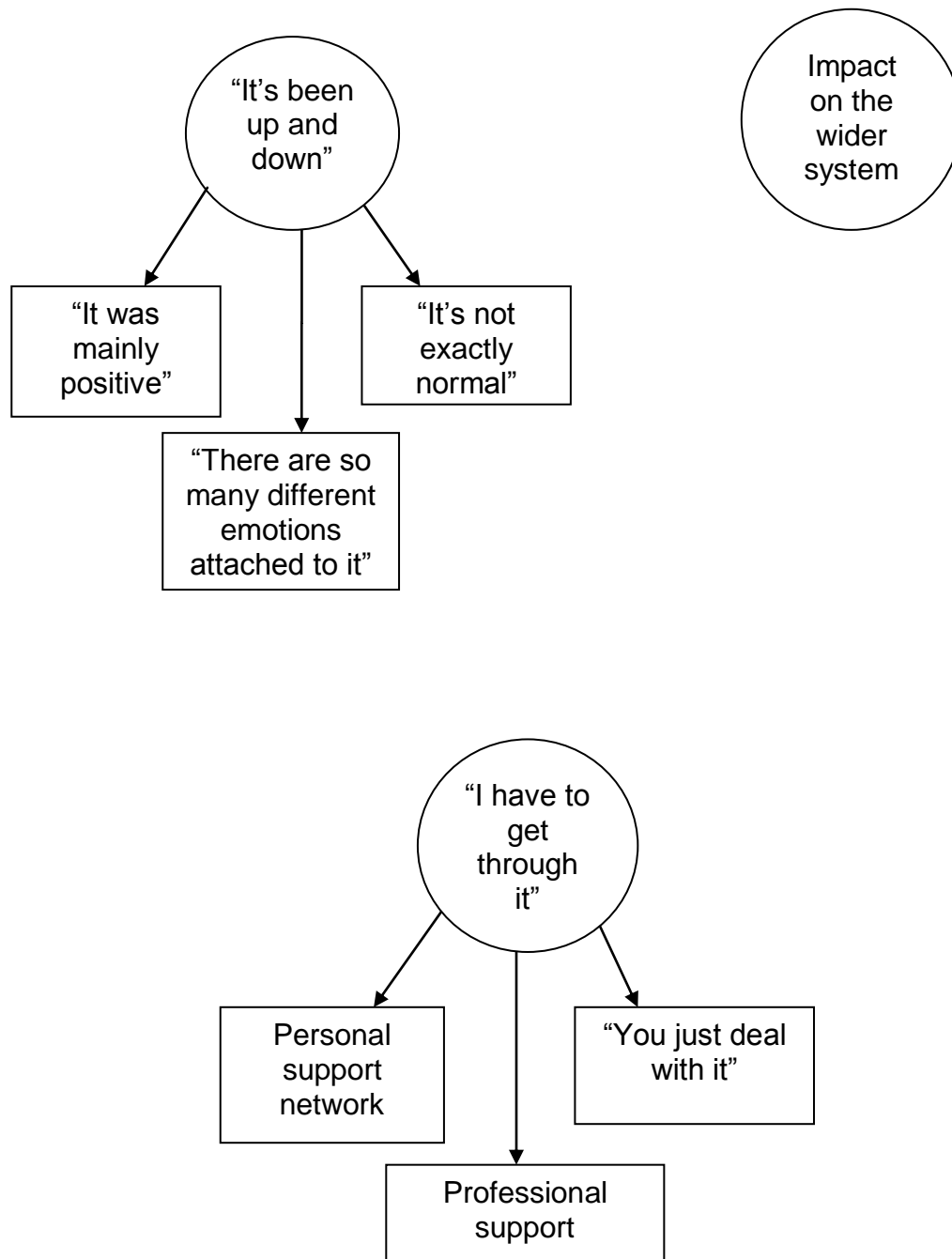
Appendix 21 – Thematic Map Two



Appendix 22 – Thematic Map Three



Appendix 23 – Thematic Map Four



Appendix 24 – Defining and Naming Themes

Name of Theme	Definition	What was of Interest/ Relevance to Research Question
Theme One: “It’s been up and down”	Cancer can affect YP’s lives in many ways, both in the short and long term	Participants expressed that they had lots of different experiences with cancer – both positive and negative
Sub-ordinate theme: “It was mainly positive”	Refers to YP’s positive experiences in their journey with cancer	YP expressed that cancer had had a positive impact on them and their lives
Sub-ordinate theme: “There are so many different emotions attached to it”	Refers to the aspects of YP’s experiences that elicited different emotions	There are many factors that can elicit different emotions
Sub-ordinate theme: “It’s not exactly like normal”	Refers to participants doing or feeling different to their peers or how they were before they had cancer	Indicates that cancer may change the way YP live their lives and the things they are and are not able to do
Theme Two: “I have to get through it”	Participants found several factors helpful in getting them through their experiences with cancer	Relevant to how people “get through” their experiences with cancer
Sub-ordinate theme: Personal support network	Refers to the support participants received from significant others and what it was they were doing that was helpful	Highlights the importance of personal support networks when living with cancer

Sub-ordinate theme: Professional support	Refers to the support participants received from professionals; both the positives and the negatives	Highlights the importance of professional support and what professional could be doing differently
Sub-ordinate theme: “You just deal with it”	Refers to the attitudes and coping mechanisms that YP used to deal with their varied experiences	Highlights the different approaches that YP found helpful
Theme Three: Impact on the wider system	Refers to the impact cancer may have on other people and how YP experience this	Highlights the impact cancer can have on YP's wider systems and how this affects YP

Appendix 25 – Evaluating Qualitative Research

Spencer and Ritchie (2012) suggest the following guiding principles may be helpful in evaluating qualitative research:

Contribution	This refers to the value and relevance of the research, in particular beyond the purpose of the study. This may be towards policy, theory, practice etc.
Credibility	This refers to the interpretive validity of the findings (i.e. their believability and the ability to see how conclusions were made). This can be evaluated using peer review and member validation.
Rigour	This refers to methodological validity which can be assessed by reflexivity, auditability (i.e. documentation of research decisions) and defensibility (i.e. justification of method, sample and research questions)

Appendix 26 – Sample Extracts from my Reflexive Journal

Interview 1: Grace

Having spoken with both Grace and her mother over the phone I arranged to visit Grace at her family home. When I arrived at their house Grace's mother answered the door and was very welcoming. She asked Grace's sister to get her out of bed as I had arrived. Grace met me and her mother in their lounge. She arrived wearing her pyjamas and apologised for keeping us waiting. I immediately noticed the possible impact cancer may be having on her as Grace was in bed when I had arrived and came to meet me wearing her pyjamas. However, I was aware that this may have been an assumption I was making.

As this was my first interview I was quite nervous. Although I had brought my interview schedule I was concerned that I would not know what follow-up questions to ask or how to keep the interview flowing. However, my nerves were quickly alleviated when I explained to both Grace and her mother the purpose of the research; they were both very welcoming and relaxed. They also alleviated my nerves when speaking before the interview began about how research, such as this project, was essential and that they thought it was important to take part.

I think Grace and I engaged well. The time seemed to go very quickly and I felt like I had heard a lot about Grace's experiences. I was also struck by her positivity and how she was able to focus on getting better and what she was able to do. She spoke about comparing herself to other young people with cancer and how cancer can have more of an impact on them and how this made her realise what she was still able to do. I remember responding explaining that I was struck by this and I wonder whether the influence of my training and my interest in strength-based therapies influenced this and the remainder of the interview.

Throughout the interview I was aware of feeling that Grace was a quiet and shy young lady. I wonder about my responses to this during the interview and whether I was able to elicit as much information as possible. I also wonder whether speaking to a female interviewer may have influenced how much and

what was said. I also left wondering about the length of the interview and the time pressure. I wonder if it was difficult for Grace to talk immediately about her experiences about cancer without having the opportunity to engage with me. This seemed apparent as, although I felt Grace and I engaged, her responses seemed to become longer as the interview went on.

Interview 9: Ahmed

I met with Ahmed at UCLH immediately after his appointment with his Clinical Psychologist. We met in a private clinic room to conduct the interview.

As soon as I met with Ahmed, I was overwhelmed by his mature and positive attitude to life and his experiences with cancer. We appeared to engage very quickly and there were several points in the interview where we both laughed. I think this may have been helpful as it seemed Ahmed felt comfortable telling me about the different experiences he had had.

During several points in our interview Ahmed spoke about helping other people or when asked directly about his experiences he responded explaining what he would advise others to do. I wonder if this reflected on the way in which the interview was set up. Before we began the interview Ahmed asked about what would happen to the results and I shared that I hoped to disseminate these so that YP had more of a voice about what affects their experience. In hindsight, I wonder if the way in which I shared this idea influenced our interview. I also think this was inevitably influenced by my epistemological position and my training.

At the end of the interview, Ahmed said that he had enjoyed taking part and shared that he had found it helpful to reflect on his experiences. He was very inquisitive about my studies and this project and I was curious about whether this had played a role throughout our interview.